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PhD theses

Title: "*It depends on our deep belief in the treatment and our values*"— Understanding HIV-positive drug users' experiences of taking Highly Active Antiretroviral Treatment in Taiwan

Szu-Szu Ho (Iris)

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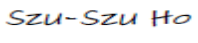
Declaration

I hereby declare that this thesis has been composed by me and that the research on which it reports is my own work. No part of this thesis has been submitted for any other degree or professional qualification

Szu-Szu Ho (Iris)

Signature: 

Lay Summary

Previous research has identified that HIV-positive drug users had poorer adherence to HIV medications compared to other HIV populations. However, there is a lack of understanding of their experiences of taking HIV medications in Taiwan. Therefore, I propose to develop a conceptual model to understand HIV-positive drug users' adherence to HIV medication using a qualitative research method. Findings from this study show that the integration of HIV-positive identity into sense of self can play an important role in self-acceptance and emotion stability. The values individuals place on HIV medications is the core and driver of their medication-taking behaviour change. Individuals' conscious engagement in medication taking can facilitate their adherence behaviour maintenance. To conclude, I believe this Identity-Values-Conscious Actions Model can provide a useful guideline for nurses to develop adherence assessment and associated interventions for drug users with the chronic HIV-positive condition.

Abstract

Background: HIV-positive drug users' poor adherence to Highly Active Antiretroviral Therapy (HAART) is a serious global health issue. Erratic use of HAART can result in incomplete viral suppression, increased Human Immunodeficiency Virus (HIV) transmission, development of drug resistance, and limitation of treatment options (Lima et al., 2008, Meresse et al., 2014, Sethi et al., 2003). In clinical practice, nurses play a key role in assessing and supporting HIV-positive drug users' health conditions and adherence to medication regimens during their treatment process. In that sense, it is pivotal to understand HIV-positive drug users' experiences of taking HAART in Taiwan.

Aim: The aims of this research are to explore HIV-positive drug users' experiences of taking HAART in Taiwan, and further develop a conceptual model synthesised from the study findings and existing theories that can enhance understanding their experiences.

Method: A qualitative study drawing from Constructivist grounded theory approach was conducted to achieve the aims. A sample of 22 HIV-positive drug users was recruited in Northern and Southern Taiwan between September 2015 and July 2016. Semi-structured in-depth interviews were conducted to explore participants' experiences of taking HAART. Data were analysed by using Charmaz's (2014) initial and focused coding principles. The integration and formation of a conceptual model began with focused coding and proceeded through the subsequent analytic process.

Findings: Three major concepts emerged in the analysis: 1) HIV-positive identity as part of self-identity, 2) Values attached to HAART, and 3) Conscious Actions. The three concepts were integrated into a conceptual model, Identity-Values-Conscious Actions Model. This proposed model suggests that individuals' integration of HIV into self-identity can lay a solid foundation for self-acceptance and emotion stability. Having this integrated identity, the values individuals place on HAART play a central role in driving

their HAART-taking. While the values individuals place on HAART can trigger behavioural changes, data revealed that implementation of conscious actions is an important element for behaviour maintenance.

Conclusion: The following conclusions can be drawn from this study. Firstly, the model developed from the study findings can extend our knowledge and understanding of the mechanism underlying HIV-positive drug users' HAART-taking behaviour in the Taiwanese context, and can act as a new reference point to contribute to the development of adherence assessments and associated nursing interventions. Secondly, the findings of this study can draw policymakers' attention to HIV-positive drug users' voice, and suggest to influence policies that can lead to a more inclusive society. Finally, building on the findings from this research and previous studies, further work needs to be done to assess whether this model can be applied to help understand HIV-positive drug users' experiences of taking HAART in different social and cultural contexts.

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Throughout this doctorate journey, I have experienced many ups and downs. However, the final outcome, the completion of this thesis, would not be possible without the assistance and support from the people who have been there for me throughout the process.

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Abbreviations

AIDS: Acquired Immune Deficiency Syndrome

ASSIA: Applied Social Sciences Index and Abstract

CDC: Centre for Disease Control

CINAHL: Cumulative Index to Nursing and Allied Health Literature

DALYs: Disability-Adjusted Life Years

DOH: Department of Health

DSM: Diagnostic and Statistical Manual

GDP: Gross Domestic Product

GPs: General Practitioners

HAART: Highly Active Antiretroviral Therapy

HIV: Human Immunodeficiency Virus

HLC: Health Locus of Control

HBM: Health Belief Model

ICERs: Incremental Cost-Effectiveness Ratios

ICO: Information Commissioner's Office

IDU: Injecting Drug Use or IDUs: Injecting Drug Users

IMB model: Information-Motivation-Behavioural skills model

LGBT: Lesbian, Gay, Bisexual, and Transgender

MEMS: Medication Events Monitoring System

MOHW: Ministry of Health and Welfare

MSM: Men who have Sex with Men

NAMI: National Alliance on Mental Illness

NCCSDO: National Coordinating Centre for NHS Delivery and Organisation

NGOs: Non-Governmental Organizations

NHI: National Health Insurance

NHS: National Health Service

NIDA: National Institute on Drug Abuse

OST: Opioid Substitution Therapy

PMT: Protection motivation theory

PrEP: Pre-exposure prophylaxis

QALY: Quality-Adjusted-Life-Year

REC: Research Ethics Committee

SDGs: Sustainable Development Goals

TB: Tuberculosis

TBNHI: Taiwan Bureau of National Health Insurance

TFDA: Taiwan Food and Drug Administration

TPB: Theory of planned behaviour

TRA: Theory of Reasoned Action

TTM: Transtheoretical Model

UK: United Kingdom

UNs: United Nations

UNAIDS: Joint United Nations Programme on HIV/AIDS

UNODC: United Nations Office on Drugs and Crime

USA: United States of America

WHO: World Health Organisation

CHAPTER ONE: INTRODUCTION

1.1. Introduction

Acquired Immune Deficiency Syndrome (AIDS)/Human Immunodeficiency Virus (HIV) was first identified in 1981 (Sharp and Hahn, 2011, Vella et al., 2012). Thirty years after its identification, at least 60 million people had been infected and more than 25 million deaths were caused by the disease (Sharp and Hahn, 2011). Following the significant impact of AIDS-related deaths, huge efforts started in an attempt to control the virus (Sharp and Hahn, 2011). In 1996, Highly Active Antiretroviral Therapy (HAART) was introduced, which has been changing the landscape of HIV, from a lethal disease to a chronic and manageable health condition (Hogg et al., 2008, Vella et al., 2012, World Health Organisation, WHO, 2014a). Since the advent of HAART, the number of people living with HIV has dropped from 60 million in 2011 to 36.7 million in 2017 (Joint United Nations Programme on HIV/AIDS, UNAIDS, 2017).

However, it was evident and widely recognised that more than 95% of prescribed HAART medications should be taken in order to achieve complete viral suppression (Paterson et al., 2000, Ortego et al., 2011, WHO, 2013). Suboptimal adherence could lead to the emergence of drug resistance and limited treatment options (Sethi et al., 2003, Lima et al., 2008, Meresse et al., 2014). As such, it highlights the importance of adherence to HAART among people with HIV. Among the general HIV population, HIV-positive drug users have been reported globally and in Taiwan to be less likely to access HIV care and adhere to treatment regimens (Ware et al., 2005, Wang et al., 2008, Yang et al., 2008a, Ortego et al., 2011, Wasti et al., 2012, World Health Organisation, World Health Organisation, WHO, 2013, Hansana et al., 2013, Chakrapani et al., 2014). In addition, the development of Tuberculosis (TB) is particularly common among HIV-positive drug users as a result of suboptimal adherence (57%) (WHO, 2017a, Deiss et al, 2009). In light of the evidence, it

is becoming extremely difficult to ignore the existence of HIV-positive drug users' suboptimal adherence to HIV care (Ware et al., 2005, Wang et al., 2008, Yang et al., 2008a, Ortego et al., 2011, Wasti et al., 2012).

Despite the importance of regularly taking HAART, there remains a paucity of evidence on HIV-positive drug users' experiences of taking HAART globally and specifically in Taiwan. The research to date has tended to focus on measuring the rates of drug users' adherence to HAART rather than gaining insight into the mechanism underlying their HAART-taking behaviour. Additionally, no qualitative research has been conducted in relation to this research topic in Taiwan and East Asia at large. This formed the basis of the research inquiry for this thesis.

Since September 2015, the United Nations (UN) has promoted 17 Sustainable Development Goals (SDGs) plan of action in an attempt to end poverty, protect the planet and ensure prosperity for all (United Nations, UNs, 2015). The understandings of drug users' experiences of taking HAART in this qualitative study in Taiwan can help to fulfil the UNs' SDGs by allowing HIV-positive drug users' voice to be heard, appropriately shaping the delivery of HIV nursing care, and informing policymakers to create an inclusive and just environment for this vulnerable population in the Taiwanese context.

The purposes of this chapter are to introduce 1) my motivation of undertaking this research in Taiwan in conjunction with the research aims and questions, 2) how this study can facilitate fulfilling the UNs' strategic policy of SDGs, 3) key terminology used in this study, and 4) the outline of this thesis.

1.2. My motivation for this research

My motivation to conduct this study with HIV-positive drug users is based on my previous clinical work experience in Taiwan. Over the period between 2009 and 2010, I worked in an infectious diseases unit as a registered nurse. While there, I had taken care of patients with HIV, tuberculosis, hepatitis, substance misuse issues or cancers. Our unit had also been identified within

the hospital as an HIV unit where patients with HIV would be admitted for undertaking treatments. The reason for this was that there were several HIV specialists based in our unit to provide specialised HIV care. While working there, I noticed that many patients with HIV appeared to stigmatise themselves. For example, upon admission, we would need to ask if patients would like to inform their family or friends of their HIV status. The majority of them preferred to not disclose their HIV status due to their feeling of shame regarding carrying HIV. There were also some patients who appeared to be rejected by their families due to their engagement in illicit drug use and other illegal activities. As such, it was fairly common to see that patients were hospitalised without the involvement of the patient's family. Without the acquisition of support from significant others, patients tended to be more isolated and less actively talked to people.

At the time of working as a nurse in Taiwan, I noticed that HIV-positive patients' psychological well-being was less likely to be taken care of by nurses. Our heavy workloads did not allow us to have time to sit down with patients and deeply understand their situations and concerns. For instance, one of my patients, who was HIV positive and had lymphoma, appeared to be distressed. Even though he had support from his family, he appeared to feel down and refused to take medications. I had tried to talk to him, however he shut himself down and did not want to talk. None of the nurses, other health professionals, and his family would be able to persuade him to take medications. I could feel that he seemed to be lost and felt hopeless. I wondered whether the patients' background and stories could shape their self perception, health decisions, and subsequent actions. However, it seemed that we did not make many efforts to deeply understand him and explore the stories behind his non-adherence to a prescribed regimen. Instead, I heard one or two of my colleagues blaming him for not taking care of himself and being irresponsible for his own health.

While working in the infectious diseases unit, patients who were HIV-positive were often combined with other comorbidities (such as cancers, tuberculosis,

hepatitis, or other infectious diseases). In particular, patients with HIV and tuberculosis needed to take several pills (more than 5 pills/per time). During patients' hospitalisation, we would administer medications and supervise their medication taking. Nonetheless, I found that a number of patients did not regularly take medications at home. Such a discovery was learnt through my communication with patients upon their admission. Asking patients about whether they had unused medications was part of our nursing assessment upon their admission. Many patients would hand over bags of their unused medications to us, and then we would administer and finish those medications first before ordering new medications. It was part of our routine, however we did not deeply understand the reasons why they did not strictly follow a prescribed regimen. In our shift reports, we rarely paid much attention to it. Instead, we complained patients did not adhere to medication regimens and wasted medical resources. Reflecting on these experiences, this has brought me to the inquiry as to why some HIV-positive patients would not regularly take antiretroviral medications and what the underlying issues were that contributed to such acts.

Having gone through the literature review on the topic of HIV-positive patients' adherence to HAART in my first year of PhD studies, HIV-positive drug users were reported to have lower adherence rates compared to the general HIV population. However, there is a paucity of research that sheds light on HIV-positive drug users' experiences of taking HAART internationally. In addition, issues relating to adherence to HAART have been predominantly approached from a quantitative perspective. In the relevant qualitative studies, HIV-positive patients' experiences of taking HAART tended to be interpreted without in-depth understandings of the underlying issues. Existing theories discussed in the **Chapter 3** were inadequately utilised so as to explain HIV-positive drug users' HAART-taking behaviour and its process. Concerned about the lack of theoretical underpinning of HIV-positive drug users' HAART-taking behaviour in the current evidence base, there is a need to develop a conceptual model synthesised from the existing theories and

study findings to gain a clear understanding of HIV-positive drug users' experiences of taking HAART.

1.3. Research aims and questions

This study set out to explore HIV-positive drug users' experiences of taking HAART, and develop a conceptual model that can unpack the complexity of their HAART-taking acts.

Drawing from a constructivist grounded theory approach, the research questions that I sought to answer for this study were:

Main research question:

What are the experiences of taking HAART among HIV-positive drug users?

Four underpinning sub-questions:

1. What meanings do HIV-positive drug users attribute to their experiences of taking HAART?

2. What is the process of their HAART-taking behaviour?

3. How are meanings of HIV-positive drug users' experiences relating to HAART taking constructed through its process?

4. What contributes to the stability and change of HIV-positive drug users' HAART-taking behaviour? Under what conditions?

1.4. Sustainable development goals and the rights of HIV-positive individuals

In 2015, 17 SDGs and a plan of action were introduced by the UNs in an attempt to meet the present needs for all without compromising the ability of future generations (UN, 2015). For sustainable development goals to be achieved, the emphasis is placed on harmonising three core elements — Economic growth, social inclusion, and environmental protection (UN, 2015,

United Nations Office on Drugs and Crime, UNODC, 2016). These elements are interconnected and all are key to the well-being of individuals and societies (UN, 2015, UNODC, 2016).

Among the 17 SDGs, SDG 3, 5, 10, and 16 are very closely linked to this study (UNODC, 2016). SDG 3's aim is to ensure healthy lives and promote well-being for all of all ages. HIV and illicit drug use can pose an impact on the health of HIV-positive drug users at individual and public health levels (Yang et al., 2008a, Gonzalo et al., 2009, Montaner et al., 2010, UNAIDS, 2016, and UNODC, 2016). Interventions in relation to prevention, treatment, rehabilitation, and social integration all play an important role in addressing issues relating to illicit drug use and HIV, and reducing their negative health impact on society (UN, 2015, UNODC, 2016). This study provides an in-depth understanding of HIV-positive drug users' experiences of HAART-taking, which in turn can inform nurses of developing tailored interventions to meet drug users' needs and optimise their health outcomes. According to SDG 5 and SDG 10— gender equality and reducing inequalities within and among countries— UNODC (2016) advocates equal access to HIV care for people who use drugs and promote services that are gender responsive. In an attempt to achieve these goals, this study provided the opportunity to give HIV-positive drug users' voices in Taiwan through interviewing. Findings from this study suggest that the creation of a just environment can enhance HIV-positive drug users' willingness to access care and without fears. In line with SDG 5 and 10, SDG 16 is to provide peaceful, just and inclusive societies. Findings from this study support a strong recommendation of the elimination of discrimination and stigmatisation towards people living with HIV and people who use drugs.

By and large, ensuring the achievement of SDGs and HIV-positive drug users' optimal adherence to HAART, this study provides several implications for the creation of an inclusive and just environment, and for the development of interventions that meet HIV-positive drug users' needs.

1.5. Terminology- compliance, adherence and concordance

There are three terms commonly used to describe medication-taking: compliance, adherence, and concordance (National Coordinating Centre for NHS Service Delivery and Organisation, NCCSDO, 2005, Cramer et al., 2008, WHO, 2013).

Compliance is defined as "*the extent to which a patient's act in accordance with the prescribed interval and a dose of dosing regimen* (Cramer et al., 2008, p.46)." The usage of this term has declined recently as it implied lack of patient involvement (NCCSDO, 2005).

Adherence refers to "*the extent to which patients' behaviours matches agreed recommendations from the prescriber* (NCCSDO, 2005, p.12)" This term is adopted more by many as an alternative to compliance, because 'adherence' involves patient's agreement to doctor's recommendations (NCCSDO, 2005, WHO 2013).

Concordance is a more recent term and is more commonly used in the United Kingdom (UK). Concordance is defined as "*an agreement reached after negotiation between a patient and a healthcare professional that respects the beliefs and wishes of the patient* (NCCSDO, 2005, p.33)." This term incorporates physician and patient's respective views to a wider concept, stretching from prescribing communication to supporting patient's medication-taking (NCCSDO, 2005).

Drawing on the definitions of the three common terms, adherence was used to describe patient's medication-taking in this thesis for two reasons. Firstly, adherence takes into account patient's agreement to medication regimens, whereas compliance does not involve patient's agreement (NCCSDO, 2005, Cramer et al., 2008, WHO 2013). Secondly, as this research focuses on the adherence behaviour of an individual without the involvement of prescribers, it may not be appropriate to use the term concordance (NCCSDO, 2005).

1.6. Describing the terms—Drug, drug use, drug addiction, drug dependence

People may use drugs for a variety of reasons. The word, drug, has two connotations. One is used in a positive way, explaining its crucial roles in medicine (Abadinsky, 2011). Another tends to be negative, reflecting self-destruction and socially deleterious patterns of misuse (Abadinsky, 2011). In this research, the word, drug, refers to illegal drugs that can lead to psychoactive effects, such as heroin, amphetamine, ketamine and ecstasy. Drug use is a generic term for the use of illegal drugs. The term has implications for excessive, dangerous, or undesirable to individual and community (Abadinsky, 2011). For the purpose of this study, HIV-positive drug users do not only refer to intravenous drug users (IDUs) but people who take illegal drugs orally. Participants in this study were classified into two main groups — 1) HIV-positive IDUs who were infected with HIV through sharing needles or other injecting equipment, and 2) HIV-positive Men who have Sex with Men (MSM) who use drugs to facilitate sexual activities (called chemsex).

Addiction is referred to as the presence of increased tolerance, withdrawal and loss of control, a compulsion to take drugs on a continuous basis, and a difficulty in refraining from a substance accompanied by negative affect experienced in its absence (Heather, 1998, National Institute on Drug Abuse, NIDA, 2016). Drug addiction does not develop overnight, whereas it is a progressive development, starting with experimental exposure and for some finally turning into addiction (Hsieh et al., 2017). The term, addiction, is not used in Diagnostic and Statistical Manual (DSM) of Mental Disorders, but approximately corresponds with the DSM definition of substance use disorder. Substance use disorder is defined by DSM as "*the condition in which the use of one or more substances can lead to a clinically significant distress or impairment* (National Alliance on Mental Illness, NAMI, 2014, p1)." In people with 'drug addiction' or 'substance use disorder', drug dependence is one of the important conditions, which occurs when the body develops and

adapts to regular exposure to a substance, leading to craving for the substance (NIDA, 2016). To effectively control heroin addiction, Opioid Substitution Therapy (OST), such as methadone, can be accessed free of charge by HIV-positive drug users in Taiwan (Ministry of Health and Welfare, MOWH, 2017).

In short, the terms, drug, drug use, addiction and dependence, were defined here to drive harmonisation of term usage throughout this thesis and enable distinction between concepts.

1.7. Structure of the thesis

In this chapter, I have

- introduced an overview of my motivation for conducting this research.
- provided the importance of this study.
- indicated what I set out to achieve in this study, and how.
- defined the key terms that will be used throughout this thesis.

The remaining chapters are organised as follows:

Chapter 2 contextualises the study in the relevant literature. This includes an overview of historical, social and political contexts in Taiwan, HIV and illicit drug use global epidemiology and in Taiwan and global policies and health policies in Taiwan in relation to HIV and illicit drug use. In addition, I will also provide a brief discussion surrounding drug-taking and health behaviour, HIV prevention and treatment, By locating the research problem in the context, this chapter provides the foundation for this study.

In Chapter 3, I explore, discuss, and critique the existing theories and models that have been applied to understand individuals' self-identity, beliefs, and health behaviours.

Chapter 4 provides a systematic and critical review of empirical studies pertaining to HIV-positive drug users' adherence to HAART. Through the

literature review, gaps and inconsistencies were identified whereby the research questions for the thesis were generated.

In Chapter 5, a detailed account is offered on methodology and methods. This includes a critical discussion around qualitative research, methodological and theoretical considerations, the elements of grounded theory approach adopted for this study. Moreover, I will also provide a discussion around the study process, such as ethical principles used in this study, recruitment and sampling, data collection, analysis process, ethical issues, and the criteria for ensuring the quality of this study.

Chapter 6, 7 and 8 offer a detailed account of the findings and analytic discussions of the data along within existing relevant literature. In Chapter 6, the concept of 'HIV-positive identity as part of self-identity' emphasises participants' experiences of being HIV positive, its emotional impact, and how the possession of the HIV-positive identity influenced their sense of self and HAART-taking behaviour. Chapter 7 focuses on how the values participants placed on HAART ignited/undermined their HAART-taking behaviour. The concept of values attached to HAART appeared to be the core concept amongst the three major concepts, and to act as a driver of HIV-positive drug users' HAART-taking behaviour. Chapter 8 provides a detailed discussion of 'conscious actions'. The concept of implementing conscious actions appeared to be key to maintain HIV-positive drug users' regular HAART use.

Chapter 9 concludes the thesis by synthesising the three concepts into a conceptual model, Identity-Values-Conscious Actions Model, which facilitates understanding the dynamics of HIV-positive drug users' HAART-taking behaviour. Furthermore, implications for nursing practice, policy and future research, contributions to knowledge, and limitations are provided at the end.

CHAPTER TWO: BACKGROUND

2.1. Introduction

This research focuses on HIV-positive drug users' experiences of taking HAART within the Taiwanese context. The importance of social context to understanding individuals' behaviour has been increasingly recognised by behavioural researchers. Social context is defined by Burke et al. (2013) as "*the socio-cultural forces that shape people's experiences and that directly and indirectly affect health behaviour* (p3)". In most social psychological theories, social, political, historical, and cultural influences upon individual behaviour are put in the position of background variables where they are acknowledged to affect individual beliefs (Ajzen, 1991, Bandura, 1991 and 2001, Berger and Luckmann, 1966, Carricaburu and Pierret, 1995, Emirbayer and Mische, 1998, Rosenstock, 1974a and b, Wallston et al., 1978). Notably, these forces are co-constituitive and formed in relation to and by each other, subsequently influencing an individual's internal belief system in ways of which the individual may not be consciously aware of (Bandura, 1991 and 2001, Berger and Luckmann, 1966, Emirbayer and Mische, 1998). These beliefs transcend individuals' values and attitudes towards objects and situations, all of which can guide and/or determine behaviour (Ajzen and Fishbein, 1977, Blumer, 1986, Rokeach, 1973).

Given the emphasis placed on the collective influence of social and individual factors on human behaviour, the following sections introduce the social, historical, cultural, and political context in Taiwan. By locating the research problem in the context, this chapter provides the foundation for the study.

2.2. Philosophies and social values in the Taiwanese society

Taiwan was first called ‘Ilha Formosa’ by Portuguese sailors, meaning ‘Beautiful Island’, when they came to Taiwan in 1544 (Rubinstein, 2006). By 1945, Taiwan had already been inhabited by the Chinese, Dutch, Spanish and Japanese for several centuries (Rubinstein, 2006, Clart and Jones, 2003). Over that period of time, residents in Taiwan mostly came from China and led a life without standardised political control by Chinese, Spanish and Dutch until the Japanese government colonized Taiwan and established effective political control over Taiwan for 50 years (Roy, 2003). However, after Japan’s defeat in World War II, Taiwan was handed back to the Republic of China governed by Chiang’s Kuomintang (KMT) party (Rubinstein, 2006). A few years later, troops of the KMT party were defeated by Communist armies due to wartime corruption and military desertion. Chiang and the remaining KMT forces fled to Taiwan in 1949 (Roy, 2003). There he re-established the government and continued operating as the Republic of China (the official name of Taiwan). Since then, Taiwan and China have been recognized as two separate sovereign states.

Berger and Luckmann (1966) in their book, “*Social Construction of Reality*”, described that by virtue of the accumulation of historical experiences, a social stock of knowledge can be constituted and transmitted from generation to generation. Drawing on this notion, Taiwan still keeps Chinese traditional values owing to the historical association with China. Although Confucianism is rooted in China, it remains intact as the core value in Taiwan and plays a central role in the Taiwanese education system. Theoretically, it entails four important principles— ‘Jen’ (benevolence), ‘Yi’ (righteousness), ‘Chung’ (loyalty), ‘Hsia’ (filial piety) (Chen, 2001).

Under this philosophy, people should be kind and considerate to others (Jen), be morally upright (Yi), be loyal to significant others (Chung), and have respect for parents and seniors (Hsia). This familial-social hierarchy in Confucianism is really an expression of respect for others in social relations

(Huang and Wu, 1994). Such a social norm includes both dominance and caretaking but is practiced in a benevolent way that focuses on the obligations within social relations rather than the restrictions placed on subordinates (Lee et al., 2007). In that sense, the core concepts of this philosophy are the emphasis of ethics, harmonious social relations and social hierarchy in the Taiwanese culture (Lin and Ho, 2009). Such cultural values are similar to the meaning of Collectivism.

Collectivism refers to the assumption that people feel the bond with social groups and have a mutual obligation (Oyserman et al., 2002). In Asian cultures, people are more concerned about behaving appropriately and adapting to different social situations (Markus and Kitayama, 1991). Such a collectivism-orientation with respect towards social commitment has become an important cultural norm shared by Taiwanese residents. In contrast with the collectivism-orientation in East Asian countries, it could be argued that individuals in Western contexts tend to focus on the primacy of the individual (individualism) (Oyserman et al., 2002, Markus and Kitayama, 1991, Lee et al., 2007).

By and large, the philosophical and historical backgrounds in Taiwan can affect individuals' ways of thinking and acting towards themselves and others (Berger and Luckmann, 1966). As the result of the normal social processes people unconsciously subscribe to and abide by, it can exert an effect on an inner sense of social difference among those who did not comply with social norms (Fine and Asch, 1988).

2.3. Religions in Taiwan

'Religion' is viewed as a high power structure comprised of beliefs, rules, rituals and practices, which can influence the way people lead their lives (Lukoff et al., 1995, Tuncay, 2007). In the Taiwanese society, religious beliefs and practices are usually polytheistic and syncretistic (Chang, 2010, Chang, 2009). Folk beliefs are considered the major traditional religions in Taiwan, a mixture of ethical ideology and the philosophies of Confucianism, Buddhism,

and Taoism (Chang, 2009, Chang, 2010, Chang and Chang, 2006). Chang and Chang's cross-sectional study of 1925 Taiwanese residents (2006) showed that 72.6% of them believed in Folk beliefs, Buddhism, and Taoism.

Due to the polytheistic and syncretistic religious beliefs in the Taiwanese culture, a strict distinction among believers of Folk religions, Buddhism, and Taoism is dubious. Most people who believe in these religions pray to various gods, deities and ancient legendary heroes (Zhai, 2007, Chang, 2010). With these traditional religions, it is believed that one's good action will be rewarded in current or future lives (Chang, 2009, Chen, 2001). Religious worship is performed for accumulating merits for the next reincarnation, and for getting blessings of good health and fortune in one's current life (Chang, 2009). As opposed to these polytheistic and syncretistic religious beliefs, Christianity is monotheistic, and the proportion of Taiwanese Christians is much fewer, accounting for 7.2% (Chang and Chang, 2006, Tao, 2008). In Christianity, people emphasise good deeds and hold the beliefs that they can have an eternal life after death (Tao, 2008). Drawing on the ideology of different religions, it can be argued that religions are based on ideologies which provide value frameworks that can guide believers in determining their attitude and behaviour of everyday life.

2.4. The economy and health system in Taiwan

Taiwan is a democratic country with an estimated population of 23 million located in East Asia (Ministry of the Interior, 2017). The economy of Taiwan has developed rapidly since the 1960s, and has been transitioned from agriculture to industrial production and information technology (Chang and Caudill, 2005, Chen, 2002). According to the International Monetary Fund (2015), Taiwan is classified as an advanced economy. National economy is linked to individual health by influencing health policy making and health services infrastructure (Osypuk et al, 2014). Due to the transition in economy, the Taiwanese government places a great emphasis on integration of technology in healthcare.

Since 1995, Taiwan has implemented a compulsory National Health Insurance (NHI) programme, which provides universal coverage to all Taiwanese citizens (Lu and Hsiao, 2003, Wu et al., 2010). The health insurance system in Taiwan is run by the Taiwan Bureau of National Health Insurance (TBNHI), and financed through a mix of premiums (Department of Health, DOH, 2012). The percentage of premium paid by the insured varies from 0% for low-income and disadvantaged citizens to 100% for self-employed citizens (DOH, 2012). In 2013, the Taiwan government and the insured/employers respectively paid 23.6% and 76.3% of the total premium (MOHW, 2013). The percentage of Gross Domestic Product (GDP) spent on health care is 6.2% in contrast to 17.1% in the United States of America (USA) and 9.1% in the UK (MOHW, 2017, WHO, 2014).

The NHI programme provides a comprehensive package of services, including preventive services, inpatient care, outpatient services, dental care, prescription drugs, laboratory and diagnostic tests, Chinese medicine, HIV medical care, harm reduction for drug users, and day care for mentally ill individuals (Lu and Hsiao, 2003, Cheng, 2003). These services are free-of-charge (Wen et al., 2008, Cheng, 2003). However, co-payments are required and paid by an insured person each time a medical service is accessed, which is approximately £2 in General Practitioner (GP) clinics and approximately £8-£10 at hospitals (Lu and Hsiao, 2003, Wu et al., 2010). For the poor, healthcare is fully subsidised by the government (Lu and Hsiao, 2003).

Under this scheme, citizens not only have equal financial access to comprehensive services but have free range to choose hospitals and physicians (Cheng, 2003). The complete freedom of choosing physicians has led to less likelihood of long waiting times for medical care. However, doctor shopping (visiting multiple doctors without professional referrals) and receiving duplicate medications had been a major concern before the adoption of new policies (Wen et al., 2008, Hsu et al., 2011). To ease such issues, the Department of Health has enhanced the capacity of electronic

prescription platforms across the boundary of hospitals, clinics, and pharmacies (Hsu et al., 2011, MOHW, 2017). As a result, it provides alerts to physicians and pharmacists when a potential duplicate medication is detected at the time of prescribing (Hsu et al., 2011, MOHW, 2017). This is unlike the health system in the UK which adopts a referral system where GPs are gatekeepers referring patients to specialist treatment (Forrest et al., 2002).

The health insurance card, called NHI-IC card, was first launched in 1999 (Liu et al., 2006). The NHI-IC card is used to record important physician orders, prescriptions, drug allergies, medical history, laboratory records, treatment history, vaccination records, and organ donation notes (Liu et al., 2006). Individuals must bring their NHI-IC card while visiting a doctor, which serves as a health passport (Liu et al., 2006). Moreover, because of its electronic nature, the NHI-IC card can function as a communication tool, which allows citizens and health care providers to access medical records electronically and manage health more effectively (MOHW, 2017, Liu et al., 2006, Lai et al., 2007). But the card cannot be read without going through strict authorization security process (Lai et al., 2007). The NHI-IC card databank centre in TBNHI serves to manage and maintain card database and a wide network of health services so that TBNHI can keep track of the insured's consumption of medical resources (Liu et al., 2006).

In addition, a current computerised surveillance system in Taiwan is also based on the IC card systems (Huang and Hou, 2007). When an emerging infectious disease occurs, the Taiwan Centre for Disease Control (CDC) can easily track suspected cases and monitor the diffusion of the infectious disease through the IC card system (e.g. HIV cases), and support better decision making with respect to treatment (Huang and Hou, 2007).

2.5. HIV and illicit drug use epidemiology

2.5.1. Global HIV epidemiology and transmission modes

In 2015, it was estimated that there were 36.7 million people living with HIV worldwide (UNAIDS, 2016). **Table 1** provides the HIV prevalence rate by global region. HIV is mainly transmitted through sexual contact, mother-to-baby transmission, or needle sharing (UNAIDS, 2016, WHO, 2017b). However, the main modes of transmission vary between countries (UNAIDS, 2016). For example, African countries had the largest HIV population worldwide (25.83 million) (UNAIDS, 2016). There, heterosexual contact and mother-to-child are the common routes of HIV transmission (UNAIDS, 2016). Asia had the second largest HIV burden after Africa with an estimate of 5.1 million HIV-positive individuals (mainly through heterosexual contact) (UNAIDS, 2016). In Eastern Europe and Central Asia, IDUs were the predominant HIV population (51%) (UNODC, 2016). In Western European and North American countries, homosexual contact appeared to be the main route of HIV transmission (UNAIDS, 2016, Centre for Disease Control, CDC, 2017b).

Table 1: **HIV prevalence by region** (UNAIDS, 2016, p2)

Region	Total No (%) Living with HIV
Global Total	36.7 million (100%)
Eastern and Southern Africa	19.4 million (53%)
Western and Central Africa	6.1 million (17%)
Asia and the Pacific	5.1 million (14%)
Western and Central Europe and North America	2.1 million (6%)
Latin America	1.8 million (5%)
The Caribbean	310,000 (<1%)
Eastern Europe and Central Asia	1.6 million (4%)
The Middle East and North Africa	230,000 (<1%)

2.5.2. HIV epidemiology and transmission modes in Taiwan

In Taiwan, the CDC (2017a) estimated that there were approximately 33,428 people living with HIV. By September of 2017, HIV infection has been mainly attributed to MSM (61.94%), followed by IDUs (19.81%) and heterosexual contact (16.71%) (**Figure 1**). The HIV-positive male drug users were mainly MSM who engaged in chemsex, followed by IDUs. As can been seen from **Figure 1**, there was a significant increase in the HIV incidence among IDUs in 2005, which was attributed to sharing needles. Since the introduction of harm reduction programmes, the HIV incidence among IDUs has dropped, from 18.2% in 2005 to 0.3% in 2010 (CDC, 2017b). HIV-infected men constitute 94.36% of the total HIV population in Taiwan (CDC, 2017a and b). The ratio of HIV-positive males to females was 19:1 by the end of 2017 (CDC, 2017a). In contrast, it was reported that there were only 917 HIV-positive female drug users across Taiwan (CDC, 2017a). Drawing on the aforementioned data, it resonates with the distribution of the HIV-positive drug users sample in this study (**Chapter 5**). Of 22 HIV-positive drug-using participants, 12 are MSM, 7 were male IDUs, and 3 were female IDUs.

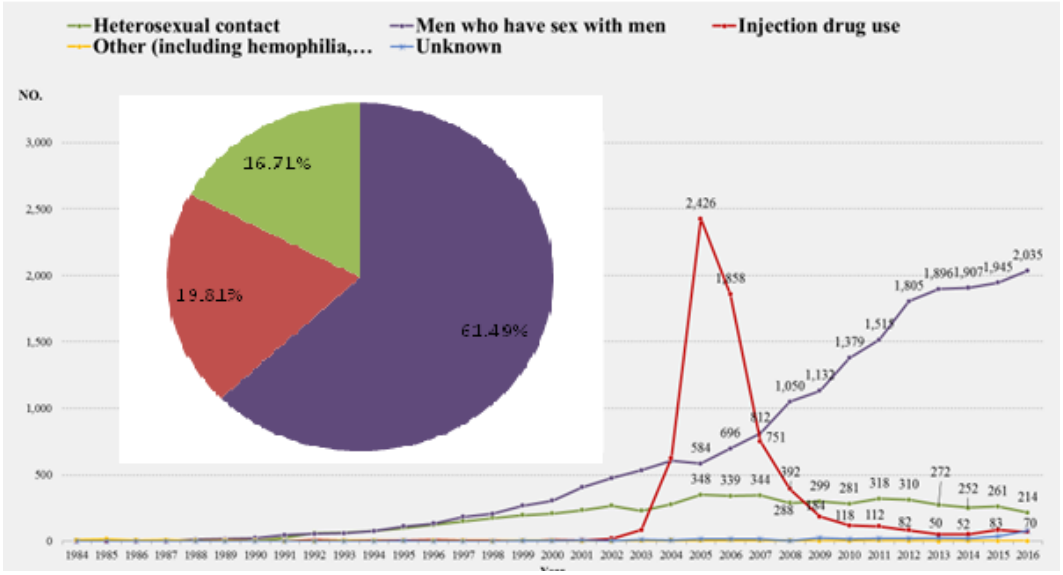


Figure 1: The prevalence of HIV transmission routes among HIV population in Taiwan (%) (CDC, 2017a, p.5)

2.5.3. Global illicit drug use epidemiology

Globally, there are 247 million people using illicit drugs, and of those 29 million people suffer from drug use disorders and 12 million people inject drugs (UNODC, 2016). Cannabis is the most commonly-used drug, with an estimate of 183 million people having used it (UNODC, 2016). Amphetamine is the second most commonly-used drugs. The use of opiates is less common, with an estimate of 33 million users worldwide (UNODC, 2016). Since illicit drug use is a criminal offence, there is a challenge of estimating illicit drug use epidemiology. In addition, there is a concern over the fact that many people who use drugs, either occasionally or regularly, tend to use more than one substance concurrently or subsequently (polydrug users). As such, the current epidemiology of illicit drug use cannot clearly capture the picture of its dynamics. (UNODC, 2016). However, such estimation can still provide an insight of its prevalence and trends.

2.5.4. Illicit drug use epidemiology in Taiwan

While cannabis, amphetamine and heroin are the top three most commonly used drugs worldwide, the trends of illicit drug use vary from country to country. According to the latest annual report of Taiwan Food and Drug Administration (TFDA, 2017), the most commonly used illicit drugs in Taiwan were heroin, methamphetamine, and ketamine. Though the estimated number of illicit drug users is not documented in the TFDA, data in relation to drug-related arrests from the study by Feng et al. (2016) are used to estimate the approximate number of illicit drug users in Taiwan. In 2014, an average of 34,948 arrestees were illicit drug users. Since 2006, the number of illicit drug users in Taiwan has increased quickly from 39,886 to 44,460 in 2007, and then gradually decreased to 31,397 by the end of 2014 due to the introduction of harm reduction and a decreased number of heroin users (CDC, 2017b, Feng et al., 2016).

In summary, the aforementioned epidemiological data imply that illicit drug use is still creating new and local HIV cases, and the ways that illicit drug use and HIV are intertwined can pose a significant threat to public health.

2.6. The impact of illicit drug use

Drug users often experience severe health-related harms associated with problem drug use and overall poor health outcomes (UNODC, 2016). The risk factors for drug users' negative health impact stem from their mode of administration of drugs and the effects of drugs. In particular, injecting drug use poses a greater risk of overdose and infections, such as blood-borne virus infections (HIV and hepatitis B and C) (Armstrong et al., 2006, Garfien et al., 1996, Platt et al., 2016). According to UNAIDS (2016), UNODC (2016) and WHO (2017b), IDUs were classified as a key at-risk population for HIV, with almost a third of new HIV infection outside sub-Saharan Africa occurring among IDUs.

Aside from IDUs, the use of stimulants has been reported to influence individuals' sexual behaviour, thereby increasing the likelihood of unprotected sexual practice and HIV transmission (Drumright et al., 2006). This pattern particularly raises concerns in the case of MSM (Drumright et al., 2006). In the same vein, Vu's (2015) systematic review and meta-analysis indicated a strong relationship between higher HIV prevalence and higher-risk sexual behaviour among MSM who used amphetamine. This indicates that illicit drug use can increase individuals' risk-taking behaviour and consequently negatively impact their health.

In *Global Burden of Disease*, WHO's (2000) estimates of global Disability-Adjusted Life Years (DALYs) attributable to opioid, amphetamine, and cocaine use suggested that use of these drugs accounted for 0.9% of DALYs in 2004 (Degenhardt and Hall, 2012). In particular, drug dependence was the largest cause of illicit drug use burden (68%), followed by HIV/AIDS infection (Degenhardt and Hall, 2012). Opioids, cocaine, amphetamine, and cannabis together accounted for almost 12 years lifelong lost due to drug-related deaths and disability (UNODC, 2016).

While the global burden of illicit drug use has been estimated, the estimates did not include socio-cultural effects that illicit drug users experience in society, such as stigma, discrimination and criminalisation (Hammersley et

al., 1990, Ahern et al., 2007, Young et al., 2005). The topic in relation to the impact of illicit drug use is under researched in the Taiwanese context. Thus, in the following, I will discuss the socio-cultural effects on drug use from international literature.

IDUs in Miller's (2008) and Kerr's (2013) qualitative studies in USA and Canada reported that living in an environment where drug abusers were treated as drug offenders and criminals, they had to hide their drug use and sometimes to share needles with other peers due to financial constraints and heavy drug dependence. This can also be seen in the example of Edinburgh in the 1980s where heroin problem was dealt with as a law enforcement issue, subsequently forcing heroin users to share needles and increasing HIV incidence (Robertson and Richardson, 2007). Criminalisation has been reported to increase the price of illicit drugs, and in turn, the high price can lead drug users to engage in criminal activities or to trade sex to finance their illicit drug use (Rácz, 2005, Degenhardt and Hall, 2012, Kerr et al., 2013). With lack of support from society, illicit drug users can form their own drug user networks and cultures (Kerr et al., 2013). The collective impact of social marginalisation and peer influence puts dependent drug users in a paradoxical situation in which they cannot escape from drug addiction and criminalising activities (Hammersley et al., 1990). Together, these aforementioned international literature showed that the laws accompanied by penalties may drive people who have already been using illicit drugs underground and make it difficult for them to re-integrate into society (Lazzarini et al., 2002).

To decrease the harms related to drug use, harm reduction programme, including needle exchange programme and methadone maintenance treatment, has been introduced (Yang et al., 2008b). The programme have been recognised globally and in Taiwan to play an important role in preventing and reducing drug users' risk-taking behaviours, such as decrease in needle-sharing, unprotected sex behaviours and overdose

(Gibson et al., 2001, Rhodes and Sarang, 2012, Barrio et al., 2012, Yang et al., 2008b).

2.7. Drug users' health behaviour

Extensive literature mainly focuses on illicit drug users' risk behaviour, whilst relatively few studies have investigated drug users' health behaviours. Individual health behaviour refers to "*any activities undertaken for the purpose of preventing or detecting disease or for improving health and well-being* (Connor and Norman, 2005, p.2)". Health has been defined by WHO as "*a state of complete physical, mental and social well-being and is not merely the absence of disease or infirmity* (Larson, 1996, p.181)" In line with WHO's definition in Larson's published article, there are a variety of factors that can account for individual differences in the inclination to undertake health behaviours, including physical, emotional, social, and structural factors (Connor and Norman, 2005).

According to UNODC (2017), only 1 in 6 drug users is in treatment. Similarly, it has been reported globally that a low proportion of HIV-positive drug users are on HIV treatment or have regular use of health services (Morrison et al., 1997, Pach et al., 2003, Lloyd et al., 2005, Davey et al., 2007, Gyarmathy and Latkin, 2008, Sarin and Kerrigan, 2012, UNAIDS, 2014). Nevertheless, in the literature, the foci of drug users' health behaviours predominantly relate to harm reduction programme, and detoxification services due to drug users' risk behaviours (Morrison et al., 1997, Pach et al., 2003, Wood et al., 2004, Lloyd et al., 2005, Davey et al., 2007, Gyarmathy and Latkin, 2008, Sarin and Kerrigan, 2012, UNAIDS, 2014).

Two cohort studies by Bell et al. (2006) in Australia and Beynon et al. (2006) in the UK indicated that drug users were more likely to have addiction treatment interruption and cycle in and out of the treatment. Drug users who sought addiction treatment were reported in the study by Morrison et al. (1997) in Glasgow to be more likely in situations where emergency or crisis occurred. In this survey with 112 IDUs who engaged in risky behaviours and

were not in addiction treatment, normalising risky behaviours and unawareness of treatment necessity were found to be the main factors that impeded their treatment-seeking behaviours (Morrison et al., 1997). On the other hand, support from friends and perceived drug problem severity have been found in the studies by Lloyd et al. (2005), Davey et al. (2007) and Gyarmathy and Latkin (2008) in USA, to be significantly associated with participation in treatment programmes. Engaging in addiction treatment was also found in the studies by Davey et al. (2007) in USA, Roux et al. (2008) in France, and Rhodes and Sarang (2012) in Russia to facilitate drug users' involvement in and adherence to HIV treatment.

Reflecting on the findings of relevant literature, the primary focused question was related to the negative impact of illicit drugs on seeking addiction treatment or the effectiveness of addiction treatment programme on health behaviour. Nonetheless, there has been little attention on the holistic view of how drug users' health behaviours are formed and sustained. It was evident in the literature that drug users' health behaviours are socially constructed and shaped by an array of physical, mental, social, and structural facets (Lloyd et al., 2005, Krüsi et al., 2010, Sarin and Kerrigan, 2012). An improved understanding of the mechanism underlying drug users' health behaviours requires further research likely to utilise novel methods of accessing an often hard-to-reach group. The in-depth understanding of drug users' experiences of taking HAART in this study will enable laws that may overemphasise penalties towards illicit drug use to be re-evaluated and refined in order to foster a more health-oriented approach to meet their needs and to optimise global health.

2.8. HIV prevention in Taiwan

In an attempt to understand HIV-positive drug users' experiences of taking HAART in this study, it is essential to gain insight into how HIV prevention and treatment are implemented in Taiwan. The first HIV case in Taiwan was reported in 1984 (Twu et al., 2004). Since then, Taiwan government has

taken many steps to prevent HIV incidence. Firstly, MSM Community Health Centres were established to provide Lesbian, Gay, Bisexual, and Transgender (LGBT) friendly health services (CDC, 2017b, MOHW, 2017). Educational materials are designed and tailored to meet the needs of a variety of HIV at-risk groups (MOHW, 2017, Twu et al., 2004). The government and Non-Governmental Organizations (NGOs) work together to reach out and distribute educational materials to the gay community, sex workers, adolescent detention centres and school (Twu et al., 2004). In addition, mass media is used as a means of promoting HIV education.

Online opinion leaders and HIV testing advertisement are set up on mobile dating apps (CDC, 2017b, MOHW, 2017). Free hotlines have been established to provide immediate and accurate health information and counselling (CDC, 2017b). Free anonymous HIV testing is provided throughout hospitals and community settings (CDC, 2017b, MOHW, 2017, Twu et al., 2004). HIV screening is also provided for pregnant women (MOHW, 2017). Condom and self-testing kits vending machines are installed in venues frequented by the HIV risk populations, such as hotels, gay bars, clubs and parks. military draftees, prison inmates, and sex workers (CDC, 2017b, MOHW, 2017, Twu et al., 2004). Individuals can get full redeem after logging in their test results online.

Despite the progress made by the prevention programmes in Taiwan, there remain new HIV cases every year in Taiwan (CDC, 2017a). More efforts are needed to achieve the UNAIDS's goal (2016) of ending HIV by 2030. In recent years, pre-exposure prophylaxis (PrEP: a course of antiretroviral medications taken by HIV-negative people at greater risk of HIV to prevent infection) has been the latest addition to efforts to expand prevention options (WHO, 2017c). Since 2017, PrEP has been approved to be provided free of charge in Scotland and Norway (Kelen and Cresswell, 2017, National Health Service, NHS Scotland, 2017), whereas PrEP is not currently covered by NHI in Taiwan.

2.9. Highly active antiretroviral therapy (HAART)

In 1997, Taiwan adopted a policy to provide HIV-affected individuals with free HIV care, including HAART and inpatient care (Fang et al., 2004). HAART is a combination of different antiretroviral drugs used to suppress HIV viral load. In the early era, HAART regimens were often complex and comprised of up to 20 pills, while to date simple, once-daily and single-pill HAART regimens have become more widely available (Raboud et al., 2011, Cooke et al., 2014, Langebeek et al., 2014, Ramjan et al., 2014, Vitoria et al., 2014). However, the provision of HAART differs from country to country depending on national economy and policies (UNAIDS, 2014). In Taiwan, a single dose is commonly used by HIV-positive individuals.

According to the WHO (2016), HIV-affected individuals are recommended to initiate HAART regardless of their clinical stage and CD4 cell count. Central to initiation of HAART is a detailed discussion about patients' willingness and readiness to receive HAART. In doing so, the WHO (2016) suggested that health care providers should assess patients' knowledge levels in relation to HIV and HAART, and their needs for psychosocial support.

Global consensus and leadership have reinforced the determination to achieve the 90-90-90 treatment target by 2020, whereby 90% of HIV-positive individuals acknowledge their HIV status, 90% of HIV-positive individuals who know their HIV status receive HAART, and 90% of people who received HAART have suppression of HIV virus loads (UNAIDS, 2016). By 2015, the number of people living with HIV on HAART has increased by about a third, reaching 17 million in 2015 compared to 15 million in 2011 (UNAIDS, 2016). In other words, there were 46% of the global HIV population (36.7 million) receiving HAART. UK is very close to UNAIDS 909090 targets, 87%-96%-94% (Public Health England, 2017). In Taiwan, these relevant data are not available on the Taiwanese government website. Without the data available, it increases the challenge of estimating the effectiveness of the delivery of HIV-related policies strategies in Taiwan.

2.10. The impact of adherence to HAART

Having successful antiretroviral treatment is dependent critically on adherence. It is evidenced that 95% of prescribed doses are needed for complete viral suppression and CD4 recovery (Paterson et al., 2000, Lima et al., 2008, Ortego et al., 2011).

Strict adherence to HAART for achieving optimal biomedical outcomes can pose a positive impact on public health and individuals' health (Yang et al., 2008a, Gonzalo et al., 2009, Montaner et al., 2010, WHO, 2013). At the population level, the effectiveness of HAART in achieving and maintaining viral load at an undetectable level has been reported to decrease HIV transmission in either serodiscordant couples or IDUs (AIDSinfo, 2015, Fang et al., 2004, Porco et al., 2004, Castilla et al., 2005, Montaner et al., 2006, Wood et al., 2012, WHO, 2016). Apart from this, sustaining viral suppression can also reduce the risk of resistance to HAART and its cross-resistance, consequently optimising treatment options (Little et al., 2002, Sethi et al., 2003).

At the individual level, although HAART cannot eradicate HIV infection, it has changed the clinical profile of HIV infection to a chronic disease (Hogg et al., 2008). The number of people living with HIV aged 50 or older has been continuing to grow, representing 12% and 30% of people living with HIV in low-and-middle-income and high-income countries respectively (UNAIDS, 2014). Congruently, Wu and her associates (2014) analysed medical records at a university hospital in Taiwan, and the results indicated more than 50 % of HIV-positive individuals were aged 50 or older. In addition to decreased mortality, HAART has been reported to increase patients' quality of life (Fang et al., 2007, Simpson et al., 2007, Gonzalo et al., 2009). The Quality-Adjusted-Life-Year (QALY) measures the extent of health gain that results from health interventions, which can be used to estimate the worth of interventions from an economic perspective. According to Fang et al. (2007), Gonzalo et al. (2009), and Miners et al. (2001), the Incremental Cost-Effectiveness Ratios (ICERs) were estimated at £14,602 per life-year saved

in the UK, $14,587 in the USA, $9,782 in Taiwan, $9,083 in Spain, $984 in South Africa. These results indicated that health expenditure on HAART is cost-effective, within savings being derived from not having to repeatedly treat patients with opportunistic infections and other societal costs (Miners et al., 2001, Gonzalo et al., 2009).

Despite the effectiveness of HAART on HIV individuals' health, there was a concern over the death caused by suicide among the HIV-positive individuals in Taiwan between 1994 and 2005 (Lu et al., 2006, and Yang et al., 2008a). In particular, HIV-positive IDUs had a higher rate of committing suicide and were less likely to seek medical care compared with the sexual transmission groups (Yang et al., 2008a, Lu et al., 2006). Drawing on such results, findings of this study can help to gain an in-depth understanding of the mechanism underlying HIV-positive IDUs' health and risk behaviour.

2.11. Summary

The background information provided in this chapter is to enhance understanding the global and Taiwanese social context in relation to HIV, HAART, and illicit drug use. According to Fesmire (2003), human life in a society consists necessarily of ongoing activities that establish or portray structure and organisation. It is the world of the objects with which people are dealing and towards which they develop their actions and behaviours (Fesmire, 2003). In reference to the notions, historical, socio-cultural and political contexts in Taiwan are introduced in this chapter to gain insight into how the society is developed and structured. While the social context is independent of individual subjective understanding, it is accessible via individual interpretations (Ritchie and Lewis, 2003). External reality is multifaceted and diverse, and such diversity adds richness to our understanding of a variety of ways in which the reality is experienced, subsequently shaping an individual's beliefs towards objects of interest and guiding behaviours (Ajzen and Fishbein, 1977, Blumer, 1986, Ritchie and Lewis, 2003, Rokeach, 1973).

Following the understandings of the global and Taiwanese social context, HIV-positive drug users' risk and health behaviours in this chapter, the next chapter focuses on theoretical literature that reveal theoretical explanations of health behaviours, and that explain the concepts relevant to study findings, self-identity and stigma.

CHAPTER THREE: THEORIES

3.1. Introduction

Research that focuses on the role of human behaviour, including health and risk behaviours, is essential for improving and optimising the health of populations (Painter et al., 2008). To date, several theories have been developed and applied to explain personal and social determinants of behaviour and to guide and refine health-related interventions (Munro et al., 2007). However, there is an increased recognition of similar and overlapping constructs across theories and models of health behaviour (Noar and Zimmerman, 2005). Difficulties can arise when an attempt is made to apply one theory or model in a study. In prevention of such duplicates, providing comparative analyses of and building on existing theories and models can help drive new development (Noar and Zimmerman, 2005).

In the current evidence base, few studies have focused on the effectiveness of the theories and models in understanding individuals' general treatment adherence (Munro et al., 2007). Despite the limitation, several theories and models have the potential to improve understanding of adherence behaviour. Therefore, this chapter aims 1) to explore, discuss, and critique the existing theories and models suggested by the WHO (2003) that can influence health behaviour and 2) introduce the concepts of the self, self-identity and stigma due to their impact on HIV-positive drug users' HAART-taking behaviour in this study.

3.2. The self

The looking-glass self theory developed by Charles Cooley (1902) describes the self as multi-dimensional. The self is shaped by our imagination of how we appear to others, of others' judgement of ourselves based on our appearance and the way we present ourselves, and of how others feel about us on the basis of the judgement they have made (Cooley, 1902). In that

sense, Cooley (1902) encapsulated the idea that our sense of self, of who we are, is intimately shaped by those around us, by our emotion and by perceived judgements; therefore, suggesting that it changes depending on which society we grow up in and situate ourselves.

George Herbert Mead (1934), uses conceptualising ideas of the separation between the “I” and the “Me”. He describes the “Me” as the organised set of attitudes of others which an individual assumes; the “I” is the response of an individual to others (Mead, 1934). Mead’s notion of the self (1934) is reliant on self-consciousness as the pre-condition for knowledge of others. This makes the development of self dependent on a concept of community. He describes self-identity along with Cooley (1902), explaining why we have several labelled identities. Several labelled identities define the reasons for our division of “self” into the “Me” and the “I”, which can shift from the one to the other. In other words, “the self” changes in different social situations as they each have changing responses through imagination which connect social and personal aspects (Mead, 1934). Furthering Cooley’s (1902) and Mead’s (1934) proposals, in Goffman’s “*The presentation of self in Everyday life*” (1959), he proposed a dramaturgical approach to the self, which he sees as a performance, with multiple roles which are both prescribed and improvised. Roles become a principal exercise when interacting with others, as is imposing identities on individuals (Goffman, 1959). In that regard, it was proposed by Goffman (1959) that roles and identities are subunits of the self.

3.2.1. Self-identity

Relevant to further elaboration of the self, Stryker and Burke (2000) in their identity theory focus on role identities, which implies a duality. Role is viewed by Stryker and Burke (2000) as external and linked to social positions. Identity is internal and consists of internalised meanings and expectations towards a role which is constructed within a system of values and beliefs and enacted through a person’s cognitive process and behaviour (Karnilowicz, 2011, Stryker and Burke, 2000). The self is comprised of the interconnecting positions and roles, each of which is linked through resources, activities, and

meanings. From this perspective, a person is embedded in multiple role relationships in different contexts and has multiple identities (Tajfel, 1982). These roles and identities may reinforce one another, but may more often do not (Tajfel, 1982). Furthering Taifel's notion, Goffman (1963) argues that social norms regarding social attributes do not determine a person's acts but rather a person can exert control over the kind of information being taken into account. Identity is, therefore, a cognitive schema where the probability of behavioural choices is in accordance with the expectation of whether the identity, relative to other identities, incorporates into the self (Stryker and Burke, 2000).

As a person reflexively interprets the identification that self and others bestow on the person self, a person's sense of self changes (Pierce et al., 2003). In the development of sense of self, ownership becomes the symbol of the self. Pierce et al. (2003) maintain that ownership manifests itself in emotion and its meaning is often associated with "my" or "mine". When an epiphany, a sudden or significant life event and experience, occurs, emotional ownership is instigated due to the influence of an epiphany on altering an individual's fundamental meaning structures (Karnilowicz, 2011). In confronting the epiphanic illness experience, reassessing self-identity becomes at the core of illness narrative (Karnilowicz, 2011). The concept of illness narrative refers to a process of a continuous account of an illness (Williams, 1984). The emergence of an illness can take a biographical shift among affected individuals, from a perceived relatively controllable and predictable life course to interrupting and damaging one (Bury, 1982).

According to biographical disruption by Bury (1982), at the earliest possible point of an illness trajectory, affected individuals can encounter problems in relation to the illness and changes in a life situation. Such uneasy balance is struck between seeing the disease as an external force but yet feeling its invasion into all aspects of an affected individual's life (Bury, 1982). In an attempt to repair ruptures between self, body, and the world, the individual's narrative has to be reconstructed by integrating one's past, perceived

present, and imagined future (Williams, 1984). This rebuilding of identity is called narrative reconstruction proposed by Williams (1984). This attempt to change the narrative is in the form of self-management to control and discipline affected individuals' lives or alternatively to accept, minimise, ignore or tolerate all that cannot be mastered (Kralik et al., 2004).

When confronted with an epiphanic illness experience, individual's self-identity is often the subject of the greatest change (Karnilowicz, 2011). The effects of the illness experience can be deliberating. Thus, during the illness process, it requires affected individuals to gain control over its effects (Kralik et al., 2004). The positioning of illness ownership and regaining control are dependent on time, situation and negotiation (Karnilowicz, 2011).

3.3. Stigma

Goffman (1963) defined stigma as a discrediting and undesirable attribute that an individual possesses. In other words, when those undesirable attributes are incongruous with the stereotype of what a given type of individual should be, stigma can occur (Goffman, 1963). In conjunction with Goffman (1963), Jones et al (1984) defined stigma as a mark which spoils individual's identity. This mark signifies undesirable characteristics or attributes. The individuals carrying this mark are perceived as responsible for creating the mark and deserving social ostracism and condemnation (Jones et al., 1984). Likewise, in 1998, Gilbert and his colleagues described stigma as characteristics of the individuals that convey a negative social identity in a social context. The costs of stigma affect not only the individuals but people surrounding them (Gilbert, Fiske and Lindzey, 1998). Based upon these historic definitions, the recent social psychologists summarise that stigma is an attribute that is marked as different and devalued in the eyes of others and it does not just occur within stigmatised individuals themselves but an entire social context as a whole (Major and O'Brien, 2005).

Stigma against illness is largely rooted in misunderstanding, discomfort and the transgression of social norms (Jones et al., 1984). Within any given

society, social norms generated, reified and perpetuated by the collective values and discourses of the members of the society constrain acceptable ways to be (Cialdini and Trost, 1998). Any transgressions of such social norms are forms of deviance, and are subject to sanctions, which serve to minimise deviation from the collective (Scambler, 2008). Illness is treated as a form of social deviance, with certain conditions facing intense stigmatisation because of the upheaval of behavioural norms that the condition brings about (Conrad and Barker, 2010).

Stigmatisation of health conditions impacts individuals in a multitude of ways, predominantly dependent on the reasons behind its stigmatisation and the visibility of the condition (Seale, 1996). For instance, HIV and drug use are commonly associated with discrediting behaviours or characteristics that are deviant from social norms, such as promiscuity, crime, sex work, and homosexuality (Carr and Gramling, 2004; Logie et al., 2011). These historic associations can lead people to generate a negative impression and prejudice towards HIV-infected drug users (Carr and Gramling, 2004, Parsons et al., 2004). As a result of being seen as culpable for their conditions, others project blame and negativity onto the individuals for the ontological disruption their conditions bring about (Corrigan, 2004, Herek, 2002). This discrimination is called an “enacted stigma”, and for those with visible signs of physical decay, the “discredited”, a risk of discrimination is ever-present (Malcolm et al., 1998, Mateu-Gaelabert et al., 2005, Scambler, 2008). Individuals living with HIV and using drugs can also experience “felt stigma”, the internalized fear of discrimination and sense of shame that living with a stigmatised condition causes (Malcolm et al., 1998). This is particularly true for the “discreditable”, where the individual’s stigmatised condition is not publicly known, and who risk consequences from exposure (Scambler, 2008). In order to combat stigma, those who possess a stigma may take action to hide HIV and drug use from others using one of two information control techniques: passing (in the case of discreditable stigma) or covering (in the case of discredited stigma) (Goffman, 1963). However, if these attempts to go unnoticed or pass as normal fail, then the risk of a stigma

becoming an individual's master status becomes a possibility (Seale, 1996). As a result, it can create barriers to seeking medical help, and lead to discrimination from medical staff and social ostracization (Alonzo and Reynolds, 1995, Crandall, 1991).

In summary, misunderstandings about HIV and illicit drug use are largely rooted in lack of knowledge, moral judgement, and fear (Ahern et al., 2007, Herek, 2002, Malcolm et al., 1998). As a result, these all perpetuate the stigma against HIV-positive drug users and trap HIV-positive drug users in a vicious cycle of shame, secrecy and isolation. In the direction of combating stigma related to HIV and drug use, measure must be taken to re-evaluate policy and service design and push for increased education.

3.4. Theories and models in relation to adherence/health behaviour

Having gone through the theoretical literature, this review was organised and divided into two sections based on the foci that the theories and models placed on: Beliefs and motivation, and control and self-regulation. The conceptual model developed in this study is underpinned from the theories and models reviewed here.

3.4.1. Beliefs and motivation

The Health Belief Model (HBM), Information-Motivation-Behavioural skills model (IMB Model), and Protection Motivation Theory (PMT) all share a cost-benefit analysis component in which an individual weighs pros and cons of taking an action, gains insight and develops beliefs through the cognitive process. In addition to the beliefs wherein the object of belief is judged to be true/false and good/bad, a value is also a belief wherein end of action is judged to be desirable/undesirable (Rokeach, 1973). All of these are key to determining the direction and intensity of an individual's motivation to act (**Appendix 2**).

3.4.1.1. Health Belief Model (HBM)

The HBM was originally developed in the 1950s, attempting to explain and predict preventive health behaviour or sick role behaviour in terms of certain belief patterns (Becker, 1974, Janz and Becker, 1984, Rosenstock, 1974b). The HBM comprises four main constructs, perceived susceptibility, perceived barriers, perceived benefits, and perceived severity (**Appendix 2**). These constructs could lead to the desire to avoid an illness or the belief that a particular action will prevent an illness (Rosenstock, 1974a). The HBM is considered important due to its influence on individual's behavioural motivation, and indirectly on behaviour (Strecher and Rosenstock, 1997).

In the field of HIV, this model has been applied to explore HIV-risk behaviour, which has been shown to significantly influence individuals' HIV-risk behaviour (Brown et al., 1991, Downing and Geisinger, 2009, Rosenstock et al., 1994, Lin et al., 2005). In terms of adherence to HAART, one cross-sectional study with 72 HIV-positive participants by Gao et al. (2010) showed that decreased perceived severity was associated with poor adherence. In addition to HIV, this model has been used successfully in predicting treatment adherence among people with psychiatric issues, obstructive sleep apnoea, and diabetes with 20-30% of the total variance (Becker and Janz, 1985, Kelly et al., 1987, Olsen et al., 2008). While the dimensions of the model exerted a significant influence on health behaviour in general, the effect size of the overall model for predicting health behaviour was small in two meta-analysis studies (Carpenter, 2010, Harrison et al., 1992). Drawing on the aforementioned studies, the variables in HBM tended to be discussed independently. Nonetheless, the relationships between the variables have not been explicitly spelt out (Armitage and Conner, 2000, Munro et al., 2007). Thus, it has been argued that the HBM is more a short list of constructs/variables than a theoretical model (Taylor et al., 2006). Furthermore, when applying this model to an individual's long-term medication adherence, factors other than health beliefs could also heavily influence an individual's adherence behaviour. For instance, cultural and socio-economic factors are not emphasised in the HBM. Despite its

limitations, this model provided valuable insight into the constructs of health beliefs for this study.

3.4.1.2. Information-Motivation-Behavioural Skills model (IMB model)

The IMB model was developed by Fisher and Fisher (1992). This model focuses on three main components that result in behaviour change: Information, motivation, and behaviour skills (Fisher and Fisher, 1992). The information and motivation components can directly influence health behaviour (Fisher and Fisher, 1992 and 2002). However, it must be noted that 'information' and 'motivation' are potentially independent constructs (Fisher and Fisher, 1992 and 2002). In other words, well-informed individuals are not necessarily motivated to engage in health behaviour. Likewise, well-motivated individuals are not necessarily well informed about the health practice. Behavioural skills are an additional determinant of whether or not people would be capable of effectively bringing about that change (Fisher and Fisher, 1992 and 2002). Behaviour skills are dependent on a person's willingness to learn and self-efficacy in carrying out health behaviour (Fisher and Fisher, 1992 and 2002). The components can also be moderated by a range of contextual factors, such as accessibility of care, or living conditions (Fisher and Fisher, 1992 and 2002).

This model has been widely used in HIV-related behaviours, such as HIV-risk behaviour, adherence to antiretroviral medications, and AIDS-preventive behaviour by the original authors (Fisher et al., 1999, Fisher et al., 2002, Fisher et al., 2006, Rongkavilit et al., 2010). The empirical studies also showed the model was moderately effective in promoting adherence behaviour in people with diabetes, and has a predictive value for adherence to antiretroviral medications among people living with HIV (Amico et al., 2005, Mayberry and Osborn, 2014, Starace et al., 2006, WHO, 2003). However, so far there are no meta-analyses identified to assess the effect of this model. In the model itself, it seems that this model does not offer a strong theoretical explanation with regards the definition of motivation and the influence of psychological aspects on behaviour. Even so, the concepts

in this model served as sensitising concepts when analysing data in this study (**Section 5.8.**).

3.4.1.3. Transtheoretical Model (TTM)

The TTM is the most prominent theory when discussing the stages of behaviour change. The TTM construes behaviour change as an individual's intentional process that unfolds over time and involves six discrete stages of change – Precontemplation, contemplation, preparation, action, maintenance, and termination (Prochaska and Velicer, 1997). These stages are not a linear but fluid process (Prochaska and Velicer, 1997). For instance, people may remain the behaviour change for the rest of their lives (termination stage), relapse (returning from action and maintenance stages to contemplation or preparation stages), or make several attempt to come back and forth between stages before their goals are realised.

Overall, the TTM has appealing features. It is intuitive and provides us insight into the process of behaviour change. Marshall and Biddle's (2001) meta-analysis showed that participants were less likely to perform health behaviour at the pre-contemplation and contemplation stages, whereas experiential processes tended to peak at action and maintenance stages. This model has not been applied in examining adherence behaviour. However, in Hall and Rossi's (2008) meta-analysis of pros and cons of change in 48 health behaviours (predominantly exercise and condom use behaviours), the results indicated that participants tended to focus on the cons of changing behaviour at pre-contemplation stage compared to at contemplation and preparation stages. It seems that the distinguishable stages in the model allow practitioners to design interventions easily. However, the main problem with the model lies in the lack of a clear specification of what leads to stage transitions. For instance, this model tells us little about in what context/situation the changes are more likely to occur. By taking into account social context and identifying turning points at each stage, it can facilitate understanding the dynamics of behaviour change in the process. In addition, concerning the complexity of human behaviour, applying stages of change to

understand adherence behaviour is beset. Behaviour/action is impacted by personal and social traits/factors an individual has/experiences (collectively and interactively), which can vary from person to person (Blumer, 1986). In that regard, the coverage and types of the process included in the model may not be able to explicitly and adequately explain human behaviour (Marshall and Biddle, 2001, Riemsma et al., 2003). Nevertheless, the stages of behaviour change proposed in this model can serve as a point of reference when looking for patterns and processes in HIV-positive drug users' experiences of taking HAART.

3.4.1.4. Protection motivation theory (PMT)

The PMT was originally influenced by expectancy-value theory (Rogers, 1975), in which behaviour is adopted due to an individual's expectation regarding the consequences of the behaviour (Edwards, 1954). In the PMT, Rogers (1975 and 1983) proposed that one's intention to protect self depends on three factors: The perceived severity of a threatening event, the probability of that event's occurrence, the efficacy of the protective response. In the later years, Weinstein (1993) included perceived self-efficacy as the fourth component. Each of these components consists of cognitive mediational processes that are categorised as two forms – threat appraisal and coping appraisal (Rogers, 1975, Weinstein, 1993). Through these cognitive processes, people evaluate threats and select coping alternatives. It was proposed that rewards will increase the probability of selecting a maladaptive response, whereas threats will decrease the probability of selecting maladaptive response (Rogers, 1975, Weinstein, 1993). The selection of adaptive coping response will depend on one's beliefs that adaptive response will work and personal ability can actually carry out the adaptive response (Rogers, 1975, Weinstein, 1993). On the other hand, perception of the costs of adaptive response will decrease the probability of selecting the adaptive response (Rogers, 1975, Weinstein, 1993).

Two meta-analyses of 65 studies by Floyd et al. (2000) and of 21 studies by Milne et al. (2000) respectively examining this theory found moderate effects

on health behaviour. Both threat and coping appraisal had modest utility in predicting an individual's intention to protect oneself against health threat (Flynn et al., 1995, Floyd et al., 2000, Milne et al., 2000). In particular, coping appraisal has been reported in the two meta-analysis studies to have greater utility compared to threat appraisal (Floyd et al., 2000, Milne et al., 2000). Flynn et al. (1995), for example, applied PMT to examine medication adherence among patients with muscular dystrophy. The strongest finding of the study was that when perceiving treatment as effective, adherence behaviour was more likely to be enacted. Another study by Van der Velde and Van der Pligt (1991) tested the theory on HIV-related health behaviour related to safe sex. The result showed that the PMT fits adequately with individuals' intentions to adopt recommended responses. Fear was particularly found to pose a direct and positive impact on behaviour intentions.

Despite its usefulness, one major drawback is that the PMT does not take into account that behaviour is not always rational. An individual may not consciously re-evaluate all of their medication-taking behaviours. In addition, this theory mainly focuses on personal factors, whereas the influence of psychological and environmental factors may also need to be taken into consideration. Thus, it has been suggested by Van der Velde and Van der Pligt (1991) that this theory should expand to consider situational factors so as to enhance understanding HIV-related health behaviour. Threat and coping appraisal in PMT is similar to perceived benefits and perceived severity in HBM, all of which were found particularly useful when exploring HIV-positive drug users' health beliefs and values in this study.

3.4.2. Control and self-regulation

In the previous section, it was discussed that personal beliefs and motivation play an important role in engaging in health behaviour. However, whether or not and how one's beliefs and motivation can be translated into action is regarded as a challenge for research. To deal with the motivation-action gap,

the theories or models in relation to control and self-regulation presented below have been proposed to help bridge the gap.

3.4.2.1.Theory of planned behaviour (TPB) and health locus of control

The TPB origins were derived from the Theory of Reasoned Action (TRA) to predict an individual's intention in behaviour at a specific time and place (Ajzen, 1985, 1991 and 2002). Intention was assumed to capture an individual's motivation that could subsequently influence behaviour (Ajzen, 1991). An individual's intention to perform a behaviour is influenced by the attitude towards the behaviour, including beliefs about the outcomes of the behaviour and evaluation of expected outcomes (Ajzen, 1991). In addition, one's intention is also influenced by subjective norms, including one's normative beliefs and motivation to comply (Ajzen, 1991, 2002).

In the TRA, it omits that one's behaviour may not always be under volitional control. Thus, Ajzen (1991) extended TPB by adding the concept of perceived behavioural control. Perceived behavioural control represents "*one's perception on the ease or difficulty of performing the behaviour of interest* (Ajzen, 1991, p183)." Perceived behavioural control may serve as a proxy for actual control over the behaviour. Conceptually, perceived behavioural control is quite similar to perceived self-efficacy and internal health locus of control. Perceived self-efficacy refers to the belief in one's ability to execute the courses of action required to obtain the attainments (Ajzen, 1991 and 2002, Bandura, 1991, Weinstein, 1993). Both perceived behavioural control and perceived self-efficacy are concerned with one's perceived ability to perform the behaviour. However, there is still a subtle difference in meaning between the two concepts, perceived behavioural control places more emphasis on 'control' over the performance of behaviour (Ajzen, 1991). In terms of internal locus control, it is a generalised expectancy that remains stable across situations and forms of actions (Norman et al., 1998, Wallston et al., 1978). By contrast, perceived behavioural control usually varies across situation and actions (Ajzen, 1991 and 2002). In other words, when individuals believe that in general their

outcomes can be determined by their own behaviour, which is internal locus control; yet at the same time, they can believe that their chance to be a lawyer is very unlikely, which is perceived behavioural control (Ajzen, 1991 and 2002).

In the current evidence base, the TPB has been widely used to explain and predict a wide range of health behaviours, and meta-analyses have supported the efficacy of the TPB for both intention and perceived behavioural control (Godin and Kok, 1996, Sheeran, 2002). The theory accounted for approximately 40-50% of the variance in intention, and 20-40% of the variance in behaviour in Godin and Kok's meta-analysis of 56 studies with 58 health behaviours and Sheeran's (2002) meta-analysis of 10 meta-analyses. Despite its efficacy, there are several limitations. Firstly, this theory does not take into account emotional factors which could potentially influence one's intention and behaviour (Munro et al., 2007). Secondly, this theory tended to assume that intention-behaviour is a linear process and does not consider it might change over time (Armitage and Conner, 2001). Furthermore, this theory assumes that 'perceived' behavioural control can influence one's behaviour, whilst it did not clearly explain how one's perceived behavioural control can influence one's actual control over behaviour. In this study, behavioural control was found to be central to HIV-positive drug users' behavioural maintenance. Therefore, findings from this study can fill the gap and add new knowledge to the current evidence base.

3.4.2.2. Social-cognitive theory – From the perspectives of self-regulation and agency

Self-regulation and agency are derived from social cognitive theory (Bandura, 1989, 1991 and 2001). The social cognitive theory was developed by Bandura (1986), which advanced a view of human functioning that accords a central role to cognitive, self-regulatory, and self-reflective processes in one's adaptation and change. In this theory, human functioning is considered as a product of a dynamic interplay of individual, behaviour, and environment (Bandura, 1991 and 2001).

From the perspective of self-regulation, an individual's behaviour is motivated and regulated by the ongoing exercise of self-influence (Bandura, 1991). Three major features of self-regulation include self-monitoring of one's behaviour and its effects, judgement of one's behaviour with regards personal standards and environmental circumstances, and affective self-evaluation that create motivators (Bandura, 1991). In addition, self-regulation also encompasses self-efficacy, which plays a crucial role in the exercise of human agency by its strong influence on thought, affect, motivation, and action (Bandura, 1991). Agency is defined by Bandura (2001) as "*acts are done intentionally* (p.6)."

From the perspective of agency, the personal level involves consciousness, the purposive use of information and self-regulation to make desired things happen (Bandura, 2001). The function of consciousness involves assessing and processing of information for regulating and evaluating courses of action (Bandura, 2001). There are four main features in agency – intentionality, forethought, self-reactiveness, and self-reflectiveness (Bandura, 2001). In the domain of intentionality, individuals are viewed as having the ability to behave accommodatively and through the exercise of self-influence. In terms of forethought, it can be presented cognitively in the present, and the foreseeable future is converted into current motivator and regulator of behaviour (Bandura, 1991 and 2001). Aside from being a planner and forethinker, self-reactiveness emphasised the execution of self-regulation and self-evaluative performance of a behaviour and goal setting (Bandura, 1991 and 2001). Self-reflectiveness focuses on self-examination of one's capacity to exercise control over behaviour and over environmental events (Bandura, 1991 and 2001).

To date, there is a paucity of empirical studies or meta-analysis that focused on the utility of social-cognitive theory in examining adherence behaviour. Few studies used this theory to understand or examine HIV risk sexual behaviour, breast-self-examination and dietary behaviour (Miller et al., 1996, Murphy et al., 1998, Safren et al., 2010, Schwarzer and Renner, 2000).

However, these studies showed that this theory could not adequately explain participants' behaviours, only accounting for small or medium proportions of variance in behaviour (Miller et al., 1996, Murphy et al., 1998, Safren et al., 2010, Schwarzer and Renner, 2000). In addition, it was found that all of the studies applied different variables/constructs derived from the theory. Such inconsistency could be argued to be due to the complex interplay presented in the theory. Even so, this theory was particularly found useful while analysing data and this provided me with a greater insight into the mechanism underlying human behaviour.

3.5. Summary

Up to now, far too little attention has been paid to understand HIV-positive drug users' experiences of taking HAART from a theoretical lens. Thus, theories and models reviewed here are in accordance to WHO's (2003) guidebook to gain a better understanding of the existing theoretical knowledge that has been used to explain health behaviour in a broader sense. In so doing, it allowed me to identify inconsistency and gaps in the existing theories and/or models. Though the aforementioned theories and models have been widely applied to explain health behaviour, only the IMB model has been extensively employed to explain HIV-positive individuals' adherence to HAART. However, this model does not provide an adequate theoretical explanation regarding how motivation is defined and the impact of psychological well-being on one's adherence behaviour.

To sum up, having gained insight into the theoretical knowledge on health behaviour, the review of empirical studies in the next chapter (**Chapter 4**) can facilitate understanding HIV-positive drug users' adherence to HAART and how their experiences were constructed, and as a result, it helps to shape the research questions in this study and my decision of the chosen research methods.

CHAPTER FOUR: INTEGRATED LITERATURE REVIEW

4.1. Introduction

The literature on HIV-positive individuals' adherence to HAART tends to reveal the importance of strict adherence. A cut-off of ≥95% or better adherence has been identified as the appropriate threshold for clinical efficacy, and this finding is replete throughout empirical research and government publications (Lima et al., 2008, NCCSDO, 2005, Ortego et al., 2011, Paterson et al., 2000, WHO, 2003). Individuals with poor adherence to long-term HAART could compromise the effectiveness of the treatment and pose a threat to the public, including incomplete viral suppression, increased HIV transmission, development of drug resistance, and limitation of treatment options (Little et al., 2002, NCCSDO, 2005, AIDSinfo, 2015).

Despite the importance of adherence to HAART, there is a growing body of literature that recognises that among the general HIV population, HIV-positive drug users have lower adherence rates compared to other HIV groups (Ingersoll, 2004, Kalichman et al., 2017, Malta et al., 2008, Martini et al., 2004, Ortego et al., 2011, Palepu et al., 2004a, Roca et al., 1999, Rosen et al., 2013, Stein et al., 2000, Yang et al., 2008b). While some research has identified drug users as a less adherent group, uncertainty remains as to why this HIV subgroup is less adherent compared to other HIV populations. In that regard, this review aims to critically review the international literature relating to HIV-positive drug users' adherence to HAART. Through a review of the literature, important insights into HIV-positive drug users' HAART-taking behaviour were gained, any gaps and inconsistencies of the current evidence base were identified, and research questions for this study were developed.

4.2. Method

Relevant studies in this review were selected by using a clear and explicit process of a literature search with pre-set inclusion and exclusion criteria. The final retrieved studies were critiqued, compared, contrasted, and synthesised based on their characteristics and findings. Through the literature review, gaps and inconsistencies were identified for generating research questions.

4.3. Search strategy

A search was performed using the databases of the Applied Social Sciences Index and Abstract (ASSIA), Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, Embase and PsycINFO (Ovid interface). The keywords used in the search were 'antiretroviral' OR 'HAART' AND 'adherence' OR 'adher*' OR 'compliance' OR 'non-adherence' OR 'non-compliance' OR 'concordance' AND 'HIV' OR 'AIDS' AND 'drug use' OR 'intravenous drug use' OR 'injecting drug use'.

4.3.1. Inclusion and exclusion criteria

Inclusion criteria	**Exclusion Criteria**
1. Studies that involved HIV-positive drug users 2. Study sample is at the age of 18 or older 3. Published in English or Traditional Chinese 4. Empirical studies that focus on adherence to HAART 5. Qualitative, quantitative, and mixed-methods studies, and dissertations (grey literature) 6. With full text	1. Studies that did not involve HIV-positive drug users 2. Study sample is less than18 years old 3. Simplified Chinese 4. Unclear study methodology 5. Studies that did not focus on adherence to HAART

Table 2: Inclusion and exclusion criteria

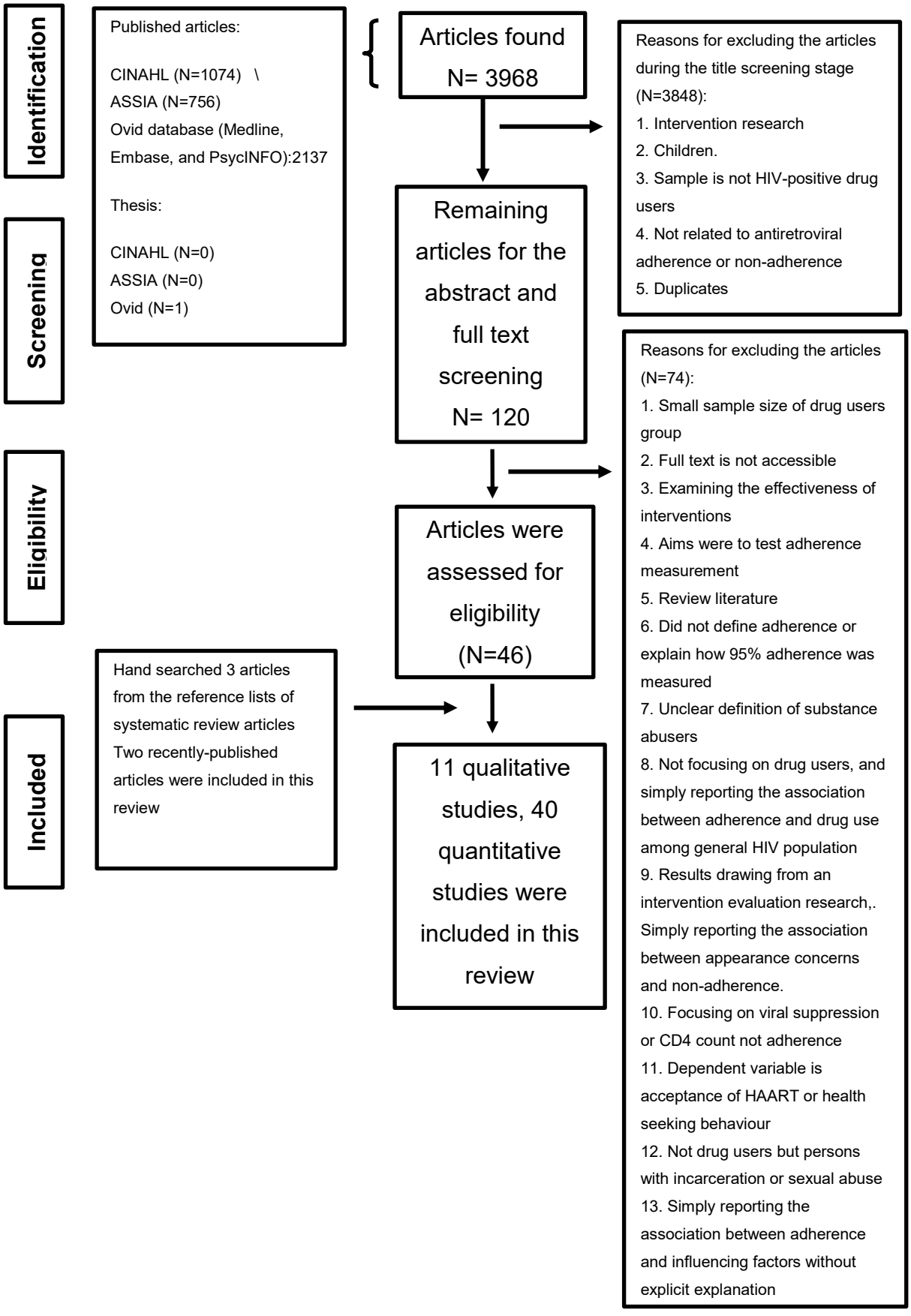
Articles published in traditional Chinese and dissertations set in the inclusion criteria are to maximise the chance of finding empirical studies relevant to the Taiwanese context. Dissertations have been categorised as grey literature (Hopewell et al., 2008), which refers to "*publications issued by government, university, business and industry in print and electronic formats but not by commercial publishers*" (Alberani et al., 1990, p.358). The inclusion of

dissertation was to reduce publication bias (Martin et al., 2005). In terms of the language selection, literature written in English and traditional Chinese, was included in the search.

4.4. Reporting study selection

Figure 2 shows the PRISMA diagram for the search that led to the final included studies in this review. This literature search included studies from 2000 to July, 2018. The literature searched was restricted to dates from 2000 onwards due to combined HAART regimens accelerated during the early 2000s, called HAART era, and the overwhelming amount of quantitative literature relating to adherence to HAART (Davis, 2006, Lu et al., 2006). Through the search strategy, 3968 articles were generated from the databases. Based on the inclusion and exclusion criteria, 3848 articles were excluded during the title screening stage, leaving 120 studies. After removal of the articles that did not meet the criteria, abstract and full-text screening eliminated further 74 articles. Five articles were hand-searched and included, leaving 51 articles for inclusion in this review. At abstract and full-text screening stage, numerous quantitative studies in relation to HIV-positive drug users' adherence to HAART were identified as opposed to qualitative studies. The study selection process and the rationale for exclusion are shown in **Figure 2**. Summary of the selected studies is presented in **Appendix 3**.

Figure 2: Flowchart of the study selection process



4.5. Results

4.5.1. Characteristics of the included studies

Of the retrieved quantitative studies (n=40), 13 were from Canada, 20 from the USA, 4 from France, 1 from the Netherlands, 1 from India and 1 from Vietnam (**Appendix 3**). Of the 13 articles from Canada, 11 were from the same prospective and ongoing research project in Vancouver. The 4 articles from France were also derived from the same prospective research project. In total, 26 articles were prospective studies (the follow-up period, ranging from 1 month to 91 months), 13 cross-sectional, and 1 secondary data analysis. There were 27 studies involving HIV-positive drug users (either illicit drug users or injecting drug users); 1 involving methadone maintained patients; 7 studies involving HIV-positive substance users with a clear sample description of what constitutes substance users; 5 studies involving HIV-positive individuals divided into subgroups (active drug users, past drug users, and non-drug users). All of the included quantitative studies recruited sample through convenient and/or snowball sampling.

The retrieved quantitative studies predominantly focused on levels of adherence, and its influencing factors, however, these studies defined adherence in a variety of ways and used different measurement tools. Most studies measured participants' levels of adherence to HAART through self-report (continuous variable: doses taken/total prescribed doses during certain period of time, or ordinal variable: self-rating adherence level), pharmacy dispensation record (the number of days patients received HAART refills/the total number of days of medical follow-up), or electronic monitoring system (Medication Events Monitoring System caps, MEMS caps). Three studies focused on drug users' discontinuation of HAART. Four measured the mean adherence rate across study participants. Of the studies measuring drug users' adherence with a continuous scale, 19 studies defined adherence as taking ≥95% prescribed doses, 2 defined adherence as taking ≥90% prescribed doses, 4 defined adherence as taking 100% prescribed doses, and 2 defined it as taking ≥ 80% prescribed doses. The quantitative findings

related to adherence rates are discussed in **Section 4.5.2**. Quantitative and qualitative findings pertaining to the factors that influence adherence are synthesised and presented in **Section 4.5.3**.

In terms of qualitative studies, 11 were retrieved for this review (**Appendix 3**). There were a paucity of qualitative research focusing on HIV-positive drug users' experiences of adherence to HAART at the literature screening stage. All the qualitative studies that involved HIV-positive drug users' experiences of taking HAART were included in this review. Although some included studies had not gone much further than describing and summarising what participants said, participants' statements presented in the studies still allows readers to see the voice of HIV-positive drug users regarding their HAART taking. In other words, the quality of these qualitative studies was assessed according to the degree to which authors represented the views of their participants (Thomas and Harden, 2008). Of the 11 qualitative studies, 2 were from Canada, 3 from the USA, 1 from Spain, 2 from Russia, 1 from Ukraine, 1 from India, and 1 from the Netherlands. In other words, there is only one relevant qualitative study in Asia. Of the included studies, 4 studies used thematic analysis, 2 used framework analysis, 1 used content analysis, 1 conducted ethnographic interviews, 2 followed Strauss and Corbin's codification process (1998), and 1 followed Glaser and Strauss's analytic approach (1967). The qualitative findings are discussed in **Section 4.5.3**.

4.5.2. An estimate of adherence levels among HIV-positive drug users

Ten studies involving only drug users and defining adherence as taking ≥95% prescribed doses revealed that drug users who had ≥95% adherence ranged from 19.3% to 85.9% (French et al., 2011, Hayashi et al., 2016, Joseph et al., 2015, Lee et al., 2016, Mann et al., 2012, Nolan et al., 2011, Palepu et al., 2011, Palepu et al., 2006, Surratt et al., 2015, Turner et al., 2003). However, this result largely represented the USA and Canada, because 7 out of the 10 studies were from Canada (Hayashi et al., 2016, Joseph et al., 2015, Lee et al., 2016, Mann et l., 2012, Nolan et al., 2011,

Palepu et al., 2011, Palepu et al., 2006), and 3 were from the USA (French et al., 2011, Surratt et al., 2015, Turner et al., 2003). Two studies from France, involving IDUs and using 80% as the cut-off point for adherence, showed that 65.2% of 164 IDUs in Moatti's study (2000) and 70% of 210 IDUs in Bouhnik's study (2002) had ≥ 80% adherence. One cross-sectional study by Arnsten et al. (2007) measured 636 HIV-positive drug users' adherence rate with use of 90% as the cut-off point for good adherence, showing that 75% of them had ≥ 90% adherence. Two studies from the USA, involving HIV-positive substance abusers (illicit drugs and alcohol abusers) and using 100% as the cut-off point, showed that 46% of 1889 substance abusers in Tucker's (2004) cross-sectional study and 55% of 1138 substance abusers in Mellins's cohort study (2009) had 100% adherence. Two prospective studies by Kalichman et al. (2015) and Ti et al. (2014) measured the average adherence rate among 85 and 587 HIV-positive illicit drug users in the USA and Canada respectively, which were reported to be approximately 50%. Compared to former drug users and non-drug users, active drug users were reported to be significantly associated with poorer adherence to HAART (Arnsten et al., 2007, Arnsten et al., 2002, Cohn et al., 2011, French et al., 2011, Hicks et al., 2007, Hinkin et al., 2007, Jordan et al., 2014, Lucas et al., 2001, Moore et al., 2012, Shape et al., 2004).

Drawing on the results, there was an indication that HIV-positive drug users had lower adherence rates. Nonetheless, a few included studies showed that HIV-positive drug users had high adherence rates. For example, one prospective study from Vietnam showed that 83% out of 100 HIV-positive drug users had perfect or very good adherence at some point (self-reported categorical scale) (Jordan et al., 2014). Another study from the USA reported that the mean adherence rates among low-income HIV-positive substance abusers ranged from 94.46%-97.97% (Magidson et al., 2015). The results are not consistent across the studies, and the aforementioned studies only measured HIV-positive drug users/substance abusers' adherence at some points. Thus, it cannot represent participants' overall adherence levels.

There are four included studies, Mann et al. (2012) from Canada, Waldrop-Valverde et al. (2013) and Hinkin et al. (2007) from the USA and Lambers et al. (2011) from the Netherlands, investigating the change in adherence levels.

The study from the Netherlands showed that 25% of 102 drug users became less adherent (was defined by the authors as < 95% adherence) at some points during the study period (Lambers et al., 2011). This indicates that adherence to HAART does not always stay at the same level. Congruently, three quantitative studies from Canada and India investigated HIV-positive IDUs' discontinuation of HAART (Hadland et al., 2012, Kerr, 2005, Sharma et al., 2007). These studies showed that 33.8% of 545 IDUs in Hadland's study in Canada (2012), 44% of 160 IDUs in Kerr's study in Canada (2005), and 32.7% of 226 IDUs in Sharma's study in India (2007) discontinued HAART during the follow-up period.

In terms of the trend of HIV-positive drug users' adherence levels over time, the prospective study from Mann et al. (2012) looked into pharmacy dispensation records, and the results showed that the proportion of achieving ≥ 95% adherence among HIV-positive drug users increased over time, from 19.3% in 1996 to 65.9% in 2009. By contrast, a prospective study from Waldrop-Valverde et al. (2013) investigated cocaine users' adherence levels using an electronic monitoring device, and the results showed that there was a significant drop in adherence from Month 1 to Month 6. The reduction in percentage dose adherence was from 76.7% at Month 1 to 66.5% at Month 6. The difference in the adherence rates over time was found to be due to personal factor in Waldrop-Valverde's study (2013) and the advance of HAART in Mann's study (2012). Mann's study (2012) investigated drug users' adherence levels over a longer period of time, from the early era of HAART to more recent era of HAART. The advance in HAART has changed the form of HAART regimens, contributing to increased adherence rates over that period of time (Mann et al., 2012). As opposed to Mann's study (2012), the follow-up period was shorter in Waldrop-Valverde's study (2013), and the

decrease in adherence rates among drug users was reported to be more associated with self-efficacy of taking HAART. In a longitudinal study by Hinkin et al. (2007), it was revealed that both drug positive and drug negative groups had a decrease in adherence rates over time. The mean adherence rate had dropped from 77.4% to 68.4% in the drug negative group, whereas there was a significant decrease in the adherence rate among the drug positive group, from 70.1% to 51.3%. The trend of the adherence rate in the entire sample was from 74.4% for the first 2 months, to 68.5% for month 3, and down to 62.6% for month 5 and 6.

By and large, the results of the included quantitative studies demonstrated the adherence rates among HIV-positive drug users, and its dynamic process. However, it is not without limitations. Firstly, as most of the included studies used convenient sampling methods to recruit participants, the adherence rates cannot be representative of HIV-positive drug users (Grove et al., 2013). Secondly, most of the included studies used self-report or pharmacy dispensation records to assess adherence rates. Self-report measure may bring social desirability bias or recall bias in research (Van de Mortel, 2008). Nevertheless, it has been reported that drug users' self-report was correlated with patients' clinical outcomes, criminal records, and interviews, and it has been tested as a reliable method (Drake, 1998). In terms of measuring adherence by using pharmacy dispensation records, issues arise as to whether patients who refill medications actually take them. This pharmacy record method has been reported by Palepu et al. (2003) as unreliable because of the insignificant association between HIV-positive drug users' adherence level and HIV-1 RNA suppression. Taking this into account, measuring adherence levels with more than one method may enhance the accuracy of adherence assessment. Furthermore, the included studies used various methods and standards to investigate drug users' adherence levels. As a result, it increased the difficulty of estimating overall drug users' adherence levels across studies.

4.5.3. Factors influencing adherence to HAART

Having gained insight into HIV-positive drug users' adherence rates in the current evidence base, this section focuses on its influencing factors. A multitude of influencing factors have been identified and explored in the included qualitative studies (n=11). Of the 11 qualitative studies, 8 involved HIV-positive individuals who had a history of injecting drugs (Chakrapani et al., 2014, de la Hera et al., 2011, Mimiaga et al., 2010, Pach et al., 2003, Rhodes and Sarang, 2012, Small et al., 2009, Witteveen and Ameijden, 2002). One involved HIV-positive active drug users (smoked/ injecting drug use) (Ware et al., 2005). One involved IDUs who use methadone maintenance (Batchelder et al., 2013). One involved HIV-positive individuals who had a history of using drugs and treatment interruption for 30 days (McNeil et al., 2017). By looking at the concepts developed from the included studies, findings were compared and contrasted, and were subsequently collated into concepts. In addition, the qualitative findings were compared with relevant quantitative results in an attempt to gain a comprehensive account of HIV-positive drug users' experiences of taking HAART.

Throughout the process of comparing findings across the included studies, six themes were identified—

1) Stigmatisation in relation to HIV and illicit drug use

2) The motivation for taking HAART

3) Active drug use and HAART adherence

4) Accessibility and conditionality of HIV and addiction treatment

5) Side effects and complexity of HAART regimens

6) Forgetting and not fitting HAART regimen into schedule.

I will now discuss the six themes in the following sections.

4.5.3.1. Stigmatisation in relation to HIV and illicit drug use

Stigma was identified as one of the predominant themes. Seven studies reported that HIV-positive drug users/inmates had experienced stigmatisation and discrimination associated with HIV and illicit drug use (Batchelder et al., 2013, Chakrapani et al., 2014, McNeil et al., 2017, Mimiaga et al., 2010, Rhodes and Sarang, 2012, Small et al., 2009, Ware et al., 2005). Some experienced violence in the prison settings (Small et al., 2009) and others were shunned and discriminated by family (Batchelder et al., 2013, Chakrapani et al., 2014, McNeil et al., 2017,Ware et al., 2005), police officers (Mimiaga et al., 2010) and health professionals (Chakrapani et al., 2014, Kiriazova et al., 2016, Rhodes and Sarang, 2012) due to their HIV status. In addition to HIV status, participants' engagement in the everyday violence associated with their drug dependence appeared to exacerbate their negative image portrayed by society (McNeil et al., 2017).

Two major factors that led to families' and public stigmatisation and discrimination towards HIV-positive drug users emerged from participants' statements across the included qualitative studies — lack of knowledge relating to HIV, and images of 'HIV and illicit drug use' discredited by society. As with lack of knowledge, misconceptions about the transmission routes of HIV were revealed to bring public fear and lead to estrangement. For example, HIV-positive drug-using participants in Mimiaga's study (2010) reported that police officers in Ukraine were afraid of them, and avoided physical contact from them or even things they had touched. As a result, their experiences of stigmatisation had influenced their willingness to access care.

Three qualitative studies from Ukraine (n=16), India (n=19), and Russia (n=42) revealed that health professionals held assumptions in relation to HIV-positive drug users' poor adherence and refused to treat them (Chakrapani et al., 2014, Kiriazova et al., 2016, Mimiaga et al., 2010, Rhodes and Sarang, 2012). Aside from health professionals' negative assumptions of drug users, Pach et al.'s (2003) (n=34) and Kiriazova et al.'s (2016) qualitative studies (n=25) indicated that some drug users did not trust health professionals,

either. This created the barrier to accessing HIV care. With a lack of engagement and trust in the health system, some drug users did not have adequate knowledge about HIV and HAART (Chakrapani et al., 2014, Pach et al., 2003, Ware et al., 2005). As a result, they were more likely to gain knowledge of HAART based on information circulating through social networks, and held negative assumptions and misinterpretation of HAART (Chakrapani et al., 2014, Pach et al., 2003, Ware et al., 2005). Congruently, Kelly's study (2012) with the use of secondary data analysis (n=76) pointed out that having HIV-positive drug users in friend circles was associated with less adherence to HAART.

Experiences of stigmatisation from families has also been reported in Chakrapani's qualitative study (2014) in India, where being HIV positive and using illicit drugs were perceived by IDUs' families to bring shame to the whole family. By holding negative perceptions of HIV and illicit drugs, some were forced by their families to move out of their house, leading to homelessness (Chakrapani et al., 2014). As a consequence, financial instabilities (e.g. lack of money, food and housing), social stigmatisation, and disruptions in drug users' daily lives had affected their ability to follow treatment regimens (Pach et al., 2003, McNeil et al., 2017, Ware et al., 2005, Witteveen and van Ameijden, 2002). Several quantitative studies also showed the significant association between homelessness and nonadherence (Arnsten et al., 2002, Bouhnik et al., 2002, Hayashi et al., 2016, Lambers et al., 2011, Palepu et al., 2006, Suratt et al., 2015).

The impact of stigmas related to HIV and illicit drug use not only impeded HIV-positive drug users' acquisition of support, but worsened their psychological distress, self-stigmatisation, and willingness to seek support (Batchelder et al., 2013, McNeil et al., 2017, Mimiaga et al., 2010, Witteveen and van Ameijden, 2002). With the feelings of denial, shame, and fear of stigmatisation, some tended to not disclose their HIV status, and were more likely to hide or not bring HAART medications with them (Batchelder et al., 2013, Mimiaga et al., 2010, Ware et al., 2005). In some cases, HIV-positive

drug users articulated their low levels of motivation to live and take HAART (Mimiaga et al., 2010, McNeil et al., 2017, Witteveen and van Ameijden, 2002).

In line with the findings derived from the qualitative studies, the included quantitative studies indicated that HIV-positive drug users' poor adherence to HAART was significantly associated with their psychological distress or depression (Arnsten et al., 2007, Mellins et al., 2009, Moore et al., 2012, Amsten et al., 2002, Carrieri et al., 2003). In addition, two studies from the USA by Magidson et al. (2015) and France by Moatti et al. (2000) indicated that environmental punishment (perception of being exposed to punishing experience) and frequency of negative life events were related to poor adherence to HAART. Of particular concern, environmental punishment was the mediator between depression and poor adherence (Magidson et al., 2015). The results illustrated the influence of social environment on individuals' psychological well-being and subsequent HAART-taking behaviour.

In brief, it seemed that stigma related to HIV and illicit drug use could pose an impact on HIV-positive drug users' acquisition of support. Without the support available for them, it can further increase drug users' levels of perceived stigma and psychological distress. Social and self-stigmatisation was revealed to be linked to misunderstandings pertaining to HIV and illicit drug users, and the influence of social values.

4.5.3.2. The motivation for taking HAART

Despite the impact of stigma on HIV-positive drug users' HAART-taking behaviour, some HIV-positive drug users appeared to be motivated to take HAART. Two factors were identified to enhance HIV-positive drug users' motivation of taking HAART— acceptance of HIV status and acquisition of support from health professionals, family or friends (Batchelder et al., 2013, de la Hera et al., 2011, Pach et al., 2003, Mimiaga et al., 2010, Ware et al., 2005, Witteveen and Ameijden, 2002). With the acquisition of support, it facilitated affected individuals' life stability and adherence to HAART by

providing tangible support (Pach et al., 2003, Mimiaga et al., 2010, Ware et al., 2005). In addition, drug users having a stable job has been identified as a factor enhancing their sense of responsibility and level of motivation to adhere to HAART (Chitsaz et al., 2013, Ware et al., 2005).

One qualitative study (n=23) by de la Hera et al. (2011) pointed out that maintaining a good relationship between health professional and HIV-positive drug users enhanced drug users' knowledge related to HAART management. In turn, drug users with adequate knowledge were found to be more likely to be aware of their HAART-taking acts and managed HAART more consciously. Aside from external support, internally, drug users' self-acceptance and wanting to live longer were revealed to strengthen their will to adhere to HAART (Batchelder et al., 2013, Mimiaga et al., 2010, Ware et al., 2005).

Drawing on the qualitative findings from the included studies, HIV-positive drug users' motivation to take HAART seemed to be influenced by the degree of support they got and their self-acceptance. As such, it had helped drug users grow belief and confidence in their capacity for taking HAART (Batchelder et al., 2013, de la Hera et al., 2011).

4.5.3.3. Active drug use and HAART adherence

The majority of the included quantitative studies indicated that illicit drug use significantly and negatively affected HIV-positive drug users' adherence to HAART (Arsten et al., 2002, Azar et al., 2015, Bouhnik et al., 2002, Carrieri et al., 2003, French et al., 2011, Hayashi et al., 2016, Hicks et al., 2007, Hinkin et al., 2007, Jordan et al., 2014, Joseph et al., 2015, Kalichman et al., 2015, Magidson et l., 2015, Mellins et al., 2009, Moore et al., 2012, Palepu et al., 2006, Roux et al., 2008, Sharma et al., 2007, Wood et al., 2004). A longitudinal study conducted in New York by French et al. (2011) investigated the impact of the change in substance abuse on participants' adherence to HAART. The result showed that participants who changed from no substance use at one interview to substance use at the follow-up interview were more likely to transition from adherence to non-adherence. However, this paper

does not specify the patterns of drug use among the participants. It would enhance understanding if this study had included more details about the dynamics of drug use as to whether participants experienced relapse or just started using illicit drugs. The tendency to use drugs to cope with stress was reported in Arnsten's prospective study (2002) to be significantly associated with non-adherence to HAART. This indicates that drugs could be used as a coping strategy by users to deal with stress, resulting in poor adherence.

Concerned about the impact of drug use on adherence, getting a fix was the heroin users' main focus (Chakrapani et al., 2014, de la Hera et al., 2011, Mimiaga et al., 2010, Pach et al., 2003, Witteveen and Ameijden, 2002, Ware et al., 2005). The large amount of time active drug users spent on pursuing their next fix had affected their ability to access health care (Mimiaga et al., 2010, Pach et al., 2003). In addition, the large sum of money spent on heroin placed HIV-positive drug users in poor financial circumstances (Witteveen and Ameijden, 2002, Ware et al., 2005). Drawing on the findings, both stigma and illicit drug use were revealed to collectively increase HIV-positive drug users' vulnerability related to incarceration, employment, family relationships, mental health, and access to care, contributing to breakdowns in the continuity of HIV care (McNeil et al., 2017, Joseph et al., 2015, Kerr et al., 2003, Lambers et al., 2011, Ware et al., 2005).

Congruent with the qualitative research findings, Mellins et al. (2009) and Tucker et al. (2004) in their cross-sectional studies reported that HIV-positive drug users' non-adherence to HAART was associated with low attendance rates at a medical appointment and poor integration of the medication regimens into their lifestyle. Wittveen and Ameijden (2002) in their ethnographic interviews noticed that the drug use patterns among drug-taking adherers ranged from using drugs once a day to using drugs once a month. Although Wittveen and Ameijden (2002) did not further explain what enabled them to regularly use illicit drugs and take HAART medications, they pointed out that methadone had alleviated participants' withdrawal symptoms and stabilised their emotions, further enhancing their adherence to HAART.

In line with this, numerous included quantitative studies also reported methadone maintenance treatment was significantly related to adherence to HAART among HIV-positive drug users (Azar et al., 2015, Hicks et al., 2007, Joseph et al., 2015, Lambers et al., 2011, Lappalainen et al., 2015, Lee et al., 2016, Nolan et al., 2011, .Palepu et al., 2006, Roux et al., 2008, Turner et al., 2003). These findings are incongruent with the results of a cross-sectional study with 133 methadone users by Shrestha and Copenhaver (2018) which indicated that methadone users were at high risk of undertaking risk-taking behaviour, and had suboptimal adherence and incomplete viral suppression.

In summary, it seemed that the addictive effects of illicit drugs could disrupt HIV-positive drug users' lifestyle and their ability to access HIV care, whereas methadone seemed to have the protective effect of alleviating their withdrawal symptoms. However, the impact of methadone use on affected individuals' drug-taking and adherence behaviour remains complex, which requires future research on their complex interplay.

4.5.3.4. Accessibility and conditionality of HIV and addiction treatment

Though HAART and addiction treatments play an important role in facilitating HIV-positive individuals' adherence to HAART, some drug users articulated the difficulty in accessing HIV and addiction care (Chakrapani et al., 2014, Kiriazova et al., 2016, McNeil et al., 2017, Pach et al., 2003, Rhodes and Sarang, 2012, Sharma et al., 2007, Small et al., 2009). The accessibility of HIV and addiction care varied from country to country. Sharma's cross-sectional study (2007) from India illustrated that the financial cost of HIV diagnostic testing, treatment of opportunistic infections, and transport significantly increased HIV-positive drug users' financial burden and impeded their access to HAART. In correctional systems, issues in relation to difficulty accessing HIV medications were reported in two qualitative studies by McNeil et al. (2017) and Small et al. (2009) in Canada. In the two studies, some participants complained about the unavailability of HIV medication between the times of arrest, trial, and arrival at the institution where they served their

sentence, and upon release from custody (McNeil et al., 2017, Small et al., 2009). As such, these structural factors increased the challenge of drug users' access to HIV care.

In addition to these structural factors, two qualitative studies from Russian and India revealed that HIV treatment conditionality was a great hindrance of access to HIV care among HIV-positive drug users (Chakrapani et al., 2014, Rhodes and Sarang, 2012). In Chakrapani's (2014) and Rhodes and Sarang's (2012) studies, physicians' provision of HAART to HIV-positive drug users appeared to be contingent. Physicians provided HAART to affected individuals, only when affected individuals could show evidence that they were reliable, deserved taking HAART, and were able to be in control of their drug use. Such value judgement was upheld by physicians' concerns in an attempt to decrease drug resistance, maximise treatment outcomes, and adapt to economic constraints within healthcare (Chakrapani et al., 2014, Rhodes and Sarang, 2012). As a result, it had led to delayed access to care, treatment interruption, or disengagement from health care among HIV-positive drug users (Chakrapani et al., 2014, Rhodes and Sarang, 2012).

Such ways of treating HIV-positive drug users situated HAART as a relative priority in the hierarchy of immediate need where managing the 'problems' of illicit drug use came first. Moreover, this policy was revealed to be put in place due to physicians' doubts of drug users' capacity to adhere to HAART in the face of ongoing and untreated drug use (Chakrapani et al., 2014, Rhodes and Sarang, 2012). In addition to the conditionality of access to HIV care, HIV-positive drug users' accounts, in the qualitative studies by Pach et al. (2003) from the US (n=34 HIV+ IDUs), Chakrapani et al. (2014) from India (n=19 HIV+ IDUs), and Rhodes and Sarang (2012) from Russia (n=42 HIV+ IDUs), showed the inadequacy and ineffectiveness of addiction treatment, and a lack of effective linkage between HIV care and drug dependence treatment/needle syringe programme. In contrast to the findings from these studies, easy access to HAART was reported by HIV-positive drug users who had a good relationship with health professionals in a qualitative study by de

la Hera et al. (2011) from Spain (n=23 HIV+ IDUs). Drawing on the findings from the aforementioned studies, it seemed that the accessibility of HIV care can also be linked to the establishment of the trusting relationship between health professionals and HIV-positive drug users.

Infrastructure within healthcare varies from country to country. Nevertheless, this could create a barrier to individuals' willingness to access care, especially for those who were in a financially disadvantaged situation. In addition, the distrusting relationship between healthcare providers and HIV-positive drug users could also widen the accessibility gap.

4.5.3.5. Side effects and complexity of HAART regimens

Side effects have been reported by several qualitative studies and one cross-sectional study as a barrier to adherence to HAART among HIV-positive drug users (Mimiaga et al., 2010, McNeil et al., 2017, Pach et al., 2003, Sharma et al., 2007, Wittveen and Ameijden, 2002). The commonly reported side effects were diarrhoea, fatigue, nausea, vomiting, and stomach-aches (Mimiaga et al., 2010, McNeil et al., 2017, Pach et al., 2003, Wittveen and Ameijden, 2002). Some had treatment interruption due to the experience of side effects (Mimiaga et al., 2010, McNeil et al., 2017, Pach et al., 2003, Wittveen and Ameijden, 2002), and others did not receive HAART because of their misconception and concerns over the toxicity and danger of taking the treatment (McNeil et al., 2017, Pach et al., 2003).

For HIV-positive drug users who started HAART in the early to mid-1990s or lived in a country where HAART options were limited (such as Ukraine), complexity of the treatment regimen was reported to influence their adherence to HAART (de la Hera et al., 2011, McNeil et al., 2017, Mimiaga et al., 2010, Wittveen and Ameijden, 2002). A qualitative study by Mimiaga et al. (2010) from Ukraine pointed out that several participants found it challenging to adhere to HAART due to high pill counts, the necessity of taking medications at specific times, and with food restrictions. Nonetheless, McNeil's study (2017) from Canada indicated that the use of modern HAART

has transformed the treatment regimens into a more simplified form, which had enhanced participants' adherence.

To sum up, the advance in HAART regimen globally has simplified the way that individuals take HAART regimens, and has decreased individuals' burden of taking HAART. Nonetheless, 'side effects' of HAART remained one of the major barriers to adherence to HAART in the included studies. Misconception and experience of side effects of HAART were found to exert an impact on receiving and/or continuing HAART among participants in the included studies.

4.5.3.6. Forgetting and not fitting HAART regimen into schedule

Fitting HAART regimen into daily schedules has been reported to bring challenges to adherence to HAART among drug users (Harzke et al., 2004, Mimiaga et al., 2010, Wittveen and Ameijden, 2002). Though this theme emerged in the included qualitative studies, there was a lack of explanation and exploration in the studies as to in what situations or how HIV-positive drug users were more likely to forget doses and not incorporate HAART into life.

To avoid forgetfulness, some HIV-positive drug users, from Wittveen and Ameijden's (2002), Mimiaga's (2010), Ware's (2005) qualitative studies, developed strategies to promoting adherence to treatment. The strategies included incorporating medication regimens into drug use routines, use of medication containers, phone alarms/alarm clocks, or stickers to remind their dosing schedules. Some took HIV medications with them all the time (Mimiaga et al., 2010, Wittveen and Ameijden, 2002).

4.6. Discussion

Evidence from the international literature has shown that HIV-positive individuals who use or inject illegal drugs were less likely to adhere to HAART and access to HIV care compared to the general HIV population (Ingersoll, 2004, Kalichman et al., 2017, Martini et al., 2004, Ortego et al.,

2011, Palepu et al., 2004a, Roca et al., 1999, Rosen et al., 2013, Stein et al., 2000, Yang et al., 2008b). Adverse effects of illegal drug use had been reported to be the major concern for non-adherence (Chakrapani et al., 2014, de la Hera et al., 2011, Mimiaga et al., 2010, Pach III, 2003, Witteveen and Ameijden, 2002). As a result, active drug use seemed to have increased the challenge of initiating and sustaining HAART use among HIV-positive drug users.

Reflecting on the included studies, it was revealed that HIV-positive drug users' HAART-taking is an ongoing and dynamic social process where the patterns of their HAART-taking behaviour did not remain the same but fluctuated over time (Lambers et al., 2011, Mann et al., 2012, Waldrop-Valverde et al., 2013). Although several attempts have been made to assess HIV-positive individuals' adherence levels by using self-reported questionnaires, pharmacy dispensing records or electronic monitoring devices, current assessment tools cannot capture the dynamic process of drug users' HAART-taking behaviour.

There are qualitative studies aimed at understanding and exploring drug users' experiences of taking HAART. In these qualitative studies, participants' experiences of stigmatisation was shown to affect their psychological well-being, self-stigmatisation, and willingness to seek support and regularly receive HAART. By contrast, self-acceptance and acquisition of support were identified to enhance HIV-positive drug users' motivation of taking HAART. In addition, active drug use, specifically heroin, was found to affect participants' decision of prioritising needs. They tended to prioritise the need of getting fixed over enhancing health condition, resulting in decreasing their motivation of taking HAART. In response to stress, drug use was reported in Arnsten et al. (2002) prospective study as a coping strategy among HIV-positive drug users. These findings imply the complex relationships between individuals' emotion, coping, and HAART-taking behaviour.

Infrastructures within healthcare were another factor shown in the included studies to impede participants' access to HIV and addiction treatment. Accessibility of care was particularly found to be linked to the economic constraints and value judgement towards drug users within the society. As for HAART regimens, concerns over side effects were revealed to shape participants' preconception of HAART and decrease their willingness to take HAART. Not fitting HAART regimen into everyday life was reported to increase the chance of missing doses.

Taken together, the findings from the included studies provide insight into the factors that influence HIV-positive drug users' adherence to HAART. However, there is much less information as to whether there is an emotional or cognitive "process" involved in drug users' HAART-taking behaviour. By understanding HIV-positive drug users' transition in emotion, thinking and HAART-taking behaviour, and their coping of the contingent situations, this can facilitate capturing their behaviour change. In addition, there remains a lack of a comprehensive understanding of HIV-positive drug users' experiences of taking HAART in the current evidence base. Uncertainty still exists about the interrelationships between factors that impact adherence, and how the factors collectively or interactively influence drug users' HAART-taking behaviour.

Within the Asian context, research on drug users' adherence to antiretroviral treatment has been focused on those countries who are members of the WHO and undertaken in low/middle-income South East Asian countries (Feelemyer et al, 2015, Wolfe et al., 2010). However, the classification of Taiwan, as a non-WHO member and high-income East Asian country, does not fit into the criteria of transitional low and middle income countries. This could be considered to be a contributing factor to the lack of research and literature in this area. The literature review conducted for this thesis has confirmed the dearth of research on this topic, therefore a study such as the one proposed here would be a useful contribution, providing new knowledge. Considering the particular socio-cultural context in Taiwan addressed in

Chapter 2 and the lack of research in this particular area as identified in **Chapter 3**, this research aims to explore Taiwanese HIV-positive drug users' experiences of taking HAART.

CHAPTER FIVE: METHODOLOGY AND METHOD

5.1. Introduction

In the previous chapter, I reviewed empirical literature on the topic of HIV-positive drug users' adherence to HAART. To date, HIV-positive drug users' adherence to HAART has been predominantly approached from a quantitative perspective. The quantitative studies showed from the review that HIV-positive drug users' HAART-taking behaviour tended to be dynamic and fluid where their HAART-taking did not stay consistent but fluctuated over the course of their treatment process. The existing qualitative evidence provided insight into HIV-positive drug users' experiences of taking HAART and its influencing factors. So far, however, there remains a paucity of evidence on how the factors interactively and collectively affect their HAART-taking behaviour during the treatment trajectory. In addition, there is a lack of theoretical underpinnings of adherence behaviour and its process. Taking these into account, it is needed to develop a conceptual model underpinned from existing theories to facilitate understanding HIV-positive drug users' experiences of taking HAART. In this chapter, I firstly discuss the qualitative method used in this study, and then moves on to discuss participant recruitment, data collection and analysis methods, and ethical issues. Lastly, the criteria I followed for enhancing the quality of this qualitative research is discussed.

5.2. Research aims

This study set out to explore HIV-positive drug users' experiences of taking HAART, and develop a conceptual model that can unpack the complexity of their HAART-taking acts.

5.3. Research questions

The research questions in this study began in an open-ended way to optimise the analytic opportunities of the study phenomenon (Charmaz, 2014, Denzin and Lincoln, 2018, Creswell and Poth, 2018). As the study progressed, questions were gradually narrowed down. The following research questions were initially formulated to explore HIV-positive drug users' experiences of taking HAART in Taiwan.

Main research question:

What are the experiences of taking HAART among HIV-positive drug users?

Four underpinning sub-questions:

1. What meanings do HIV-positive drug users attribute to their experiences of taking HAART?

2. What is the process of their HAART-taking behaviour?

3. How are meanings of HIV-positive drug users' experiences relating to HAART taking constructed through its process?

4. What contributes to the stability and change of HIV-positive drug users' HAART-taking behaviour? Under what conditions?

These questions were used to explore HIV-positive drug users' experiences of their engagement with HAART taking in the context of illicit drug use. Since HIV infection is a long-term health condition, this study also focuses on "process" to identify the dynamics of HIV-positive drug users' HAART taking. "Process" was depicted by Birks and Mills (2011) and Corbin and Strauss (2008) as not being limited by conceptions of time, phases or stages but seen as occurring in all aspects of the dynamic nature of life. Taking this notion into account, the non-linear conceptualisation of 'process' might fit well with the chaos observed in HIV-positive drug users' lives based on my previous work experience. Some drug users whom I took care of appeared to have treatment interruptions from time to time and were hard to be contacted.

Thus, with this in mind, it allowed me to consider chaos as 'process'. In this study, I would not just look for stages or phases of HIV-positive drug users' HAART-taking but explore its dynamics.

5.4. Theoretical perspectives of this study

5.4.1. The study of experience

Qualitative research is a major research method of inquiry in social sciences, encompassing a wide range of phenomena (Daher et al., 2017, Silverman, 2016). Drawing on the research questions discussed in the last section, this study focuses on participants' experiences of taking HAART. Experience is a crucial concept for obtaining a deeper understanding of an individual's perspective, and improving qualitative comprehension of the phenomenon being studied (Daher et al., 2017, Polkinghorne, 2005, Silverman, 2016). According to Dilthey (1989), experience has two aspects in it, inner experience, which addresses the experience of inner thoughts and feelings, and outer experience, which relates to outside world. While inner and outer experience can be defined independently, it is important to note that both are connected and formed as a continuous whole (Daher et al., 2017, Dilthey, 1989). In other words, understanding an individual's experience involves a process of reflective thinking about the world and constructing meanings based on the individual's accumulated experiences (Daher et al., 2017, Dilthey, 1989).

Experience has its depth, and the use of quantitative research is often inadequate to capture the richness and fullness of participant's experience (Denzin and Lincoln, 2018). Instead, the experience of an individual is often the area that qualitative research is designed to study (Polkinghorne, 2005, Silverman, 2016). However, the interpretive nature of experience means that it is internal not visible to the other except through interaction (Laing, 1967). Experience is most commonly visible through narrative means; people create and express their experience by constructing them in a narrative form (Gee, 1991, Riessman, 1993). Thus, researchers studying individual experience

gather self-report data often using interviews (Berger and Luckmann, 1966, Denzin and Lincoln, 2018, Polkinghorne, 2005, Silverman, 2016).

This exploration of participants' experiences results in data which are not formed simply by single words but by interrelated words combined into sentences, forming into discourses (Clake, 2005, Polkinghorne, 2005). In discourses, they are context-specific, reflecting participants' interactions with society, shaping meanings of their experiences being constructed (Blumer, 1986, Clarke, 2005, Denzin and Lincoln, 2011, Mishler, 1986, Sliverman, 2016). Such interconnections and complex relations and layers of participants' experiences presented in the data are an ongoing flow, not rigidly ordered, and are eternally incomplete (James, 1975). Due to the ongoing flow of experience and meaning-making, researchers can but capture it as a reflection, as a memory of what was (Schutz, 1967).

This study strives to learn the meanings of participants' experiences of taking HAART within the Taiwanese context. However, meanings a person has for HAART taking may differ from person to person (Berger and Luckmann, 1966, Blumer, 1986). Meanings are created in each individual's encounters with the world and his/her interactions with others, and the meanings are used as the basis for directing the actions (Blumer, 1986, Clarke, 2005, Daher et al., 2017). In that regard, there is no single reality for a thing, but rather the reality of everyday life is characterised by a coexistence of multiple realities in the context (Berger and Luckmann, 1966).

Drawing on these standpoints, HIV-positive drug users' HAART-taking behaviour is constructed through the meanings they attached to HAART. The meanings participants hold for HAART taking may differ depending on their interactions and communications with the social environment. In an attempt to make sense and gain insight into participants' HAART-taking experiences in terms of the meaning they bring to it, this qualitative study illuminates HIV-positive drug users' multiple perspectives on HAART taking and their social relations (Creswell and Poth, 2018).

5.4.2. Social constructionism

Social constructionism is rooted in symbolic interactionism, and started to have its hold after Berger and Luckman (1966) published "*The social construction of reality*" (Hibberd, 2005). In their book, it was argued that social phenomena are socially constructed by people through social practices (Burr, 2015). In the same vein, ontology and epistemology with their root in social constructionism follow relativism and subjectivism, which emphasise the impact of history and culture on knowledge formation and the role of language (Burr, 2015, King and Horrocks, 2010). Within social constructionism, it argues that the ways individuals understand the world are culturally and historically specific, and its aim of social inquiry is towards a consideration of how knowledge is formed by people in interaction (Burr, 2015, Creswell and Poth, 2018). As for its focus on the role of language, that is the belief that language itself has its potential to construct a reality, and the reality interpreted by researchers through language is already a form of subjectivity and is not value-free (Ritchie et al., 2014, King and Horrocks, 2010). In that sense, rather than having meanings of the world that exist independently from researcher's interpretation, constructionists assert that knowledge is co-constructed by the researcher and the researched (Denzin and Lincoln, 2018, King and Horrocks, 2010). Researchers cannot separate themselves from the world and view the world with no position (King and Horrocks, 2010). This contrasts with positivism where knowledge is objective and separate from the person and the world (King and Horrocks, 2010).

Another notion emphasised in social constructionism is that a social reality cannot be understood completely (Ritchie et al., 2014). At different times or places, there would also be different interpretations of the same phenomenon (King and Horrocks, 2010). In a similar vein, Ritchie et al. (2003) maintained that meanings attached to individual thinking and behaviour are a product of time and place, and are not fixed. Reality, therefore, acts as a point of reference but is always in a continuous state of construction, and still awaits part of its completion from the future (Bryman, 2012, James, 1975).

Drawing on the ideology of constructionism, in this study, I looked for the complexity of views rather than narrowed the meanings into few ideas. The diversity of perspectives could add richness to the understanding of various ways in which the reality of taking HAART was experienced by HIV-positive drug users (Ritchie et al., 2003). Given the emphasis placed on socially-constructed realities in social constructionism, I recognised that people's contextual circumstances can shape their interpretation of taking HAART (Denzin and Lincoln, 2018). Thus, while collecting and analysing data, this study took into account the contexts in which HIV-positive drug users lived, and how they interacted and negotiated with the environment.

5.4.3. Drawing on constructivist grounded theory approach

Among all the qualitative research methods, grounded theory approach was drawn from for this qualitative study. Because this method provides the guideline to identify categories, analyse and situate processes, identify what contributes to stability and change, demonstrate contexts, make links and relationships between categories, refine and integrate them to ultimately develop a conceptual model (Charmaz, 2006, Denzin and Lincoln, 2011). Grounded theory included five essential elements (theoretical sensitivity, constant comparison, memo writing, theoretical sampling, and theoretical saturation) and coding principles (initial coding and focused coding). These elements are unpacked in the later sections when introducing data collection and analysis methods. This section aims to discuss as to why constructivist grounded theory approach was drawn from.

In grounded theory, there are two major types of grounded theory approach, one with positivist tradition and the other with constructivist tradition. In contrast to the positivist approach of grounded theory by Glaser and Strauss (1967), Charmaz (2006 and 2014) emphasises constructivism in grounded theory. Constructivist grounded theory lies in the interpretive tradition. Interpretive tradition views theoretical understandings as abstract and interpretive rather than explanatory (Charmaz, 2006 and 2014). Constructivist grounded theory sees that data are interpreted by research

participants, but also acknowledges that the resulting theory also involves researcher's interpretation (Charmaz, 2006 and 2014). In addition, constructivist grounded theory stresses that any analysis is contextually situated in time, place, culture, and context, seeing that facts and values as linked (Charmaz, 2006 and 2014). By locating knowledge in this way, it links the subjective and the social. Considering Charmaz's (2014) grounded theory underpinned by constructivism, this study drew on her approach to interpreting data (**Section 5.8.4.**).

Under the influence of Charmaz's constructivist grounded theory (2006), Corbin and Strauss's latest edition of *Basics of Qualitative Research* (2008) showed that there is a shift away from the objectivist stance. Corbin and Strauss's (2008) emphasis of bringing 'process' and 'context' into the analysis is congruent with the standpoints in social constructionism. Corbin and Strauss (2008) take into account action/interaction, its movement, sequence, and change as well as how it changes in response to contingencies. They notice how context and conditions influence the outcomes of a set of actions/interactions (Strauss and Corbin, 1998). As a result, Corbin and Strauss (2008) have moved further from postpositivism and more towards social constructionism (Charmaz, 2014). Their approach of data contextualisation and process recognition provides a clear account of how to contextualise the data and identify a process within the data, which was found particularly useful when analysing data in this study (**Section 5.8.4.**).

One of the main differences between Charmaz's approach (2014) and Corbin and Strauss's (2008) approach is "abduction". Grounded theory is generally regarded by constructivist grounded theorists as an inductive and deductive approach (Charmaz, 2014, Corbin and Strauss, 2008). Theory is grounded from data, whilst interpretation is also a form of deduction (Clarke, 2005). Nonetheless, abduction has been recently noted and embraced by Charmaz (2014), which is defined as "*all plausible theoretical explanations during the period of data collection and analysis, the formation of hypotheses for each*

possible explanation, and checking these hypotheses empirically by examining data to arrive at the most plausible explanation (p.201)." As opposed to Charmaz (2014), reviewing theoretical literature after data collection is embraced by Corbin and Strauss's (2008). In this study, the inductive and deductive approaches were used during data collection and analysis. I did not draw on abductive reasoning during data collection, but instead, I started reviewing theoretical literature after data collection and preliminary data analysis (**Section 5.4.4.**). This allowed me, as a novice researcher, to not be immensely influenced by existing theories, and provided a space for creative thinking during preliminary data analysis.

In summary, due to social constructionism held in this study, Charmaz's (2014) and Corbin and Strauss's (2008) grounded theory approach provided suitable guidance for answering the research questions of this study. Birks and Mills (2011) suggested that it is not necessary to subscribe to one particular school of grounded theory throughout the study. A researcher with a particular philosophical position can determine whether the researcher aligns herself with one particular author, or perhaps draw from each of the grounded theory approaches to varying degrees in the application of essential grounded theory methods (Birks and Mills, 2011). Given this notion, I relished the flexible and unrestricted potential that it afforded me. In the meantime, I exploited a grounded theory approach with the constructivist position where practical to allow the research problem to become delineated as I engaged with the data.

5.4.4. Theoretical sensitivity

To conduct qualitative research drawn from grounded theory approach, researchers should be equipped with theoretical sensitivity (Charmaz, 2014). Theoretical sensitivity is defined by Strauss and Corbin (1998) as '*having insight into, and being able to give meaning to, the events and happenings in data* (p.46).' A literature review can be used as a possible source of inspiration, creative ideas, critical reflection and multiple lenses to examine data so as to arrive at the most plausible explanation (Charmaz, 2014). In

addition, during the study process, researchers can gain theoretical sensitivity through looking into studied life from multiple vantage points, making a comparison and contrast, following leads, and building on ideas (Charmaz, 2014). As opposed to Glaser and Strauss's (1967) notion that grounded theorists should stay objective and not review literature during the study, both Corbin and Strauss (2008) and Charmaz (2014) embrace literature review during the study. Comparing the two schools, Charmaz (2014) suggested literature review during theoretical sampling which is called informed grounded theory by Thornberg (2012).

However, Corbin and Strauss (2008) maintained research studies can be reviewed before the study starts, but theoretical literature should be reviewed at the later stage of the study to avoid limiting researchers' analytic thinking. The timing of the literature review in this study accords with Corbin and Strauss's (2008) notions. Before this study started, I reviewed empirical studies to formulate research questions (Corbin and Strauss, 2008). The literature provided insight into and guided where I should go to investigate HIV-positive drug users' experiences of taking HAART. Then after completion of data collection and preliminary data analysis, I turned to empirical and theoretical literature. At the later stage of data analysis (full and detailed analysis), I compared findings with existing theoretical literature to identify similarities and differences, and added new knowledge to the current evidence base. Similarly, Corbin and Strauss (2008) suggested that the review of theoretical literature at the later stage of the study can help confirm the findings in the writing stage.

As a novice researcher, I believe that if I had read many theories before and during data collection and preliminary data analysis I would be easily influenced and guided by the relevant theories. Creativity is one of the important elements in qualitative research (Patton, 2005). Analysing data requires researchers to see data from different angles, and reading theoretical literature during data collection and preliminary data analysis

might impede the open endedness and exploratory character of coding and close off my innovative analytic contribution (Van den Berg, 2008).

I acknowledge that without reviewing theoretical literature during data collection and preliminary data analysis I might run the risk of being theoretically insensitive and rehashing old empirical problems (Charmaz, 2014).

5.4.5. Reflexivity

To develop theoretical sensitivity, reflexivity should be applied throughout the research process (Charmaz, 2014). Reflexivity is defined as "*the researcher's ability to be able to self-consciously refer to her or himself in relation to the production of knowledge about research topics* (Roulston, 2010, p. 116)." In qualitative research, the idea of reflexivity has evolved due to large debates over problems of representation in research (Creswell and Poth, 2018). The key concern is that findings in qualitative research are not as straightforward as those in quantitative research (Charmaz, 2014).

As discussed earlier, constructivist tradition emphasises that researchers are an integral part of the research process (Charmaz, 2014, Creswell and Poth, 2018, Denzin and Lincoln, 2018). In that sense, researchers should be reflexive about their background, pre-conceived ideas and assumptions, positions and power dynamics with research participants, decisions relating to sampling and interview questions, and how data are interpreted (England, 1994, Mauthner and Doucet, 2003, Pillow, 2003, Roulston, 2010). Without examining researchers' preconceptions, their biases, assumptions, or beliefs could intrude into the analysis and impose a pre-existing frame on it (Charmaz, 2014, England, 1994). To minimise the intrusion of taken-for-granted assumptions, I wrote research memos constantly during the study process. In doing so, it contributed to not only producing knowledge that facilitated understanding HIV-positive drug users' experiences of taking HAART but also giving insight into how such knowledge was situated and produced (Pillow, 2003). Individuals' reflexivity can be informed by the discipline that they comes from and their theoretical framing for research

(Mauthner and Doucet, 2003, Roulston, 2010). In light of Roulston (2010), my clinical background and particular ontological and epistemological assumptions held guided what I have brought to research inquiry, how I have situated myself in this study, and my decisions with regards the methods of data collection and analysis used in this study.

As reflexivity was applied throughout the research process, I reported my personal influence and justifications for important procedural decisions regarding sampling, data collection, and data analysis. Given this notion, reflexivity has been used by many scholars in qualitative research for the purpose of increasing transparency and trustworthiness of research findings (Charmaz, 2014, Doucet, 2008, England, 1994, Gentles et al., 2014, Mauthner and Doucet, 2003, Pillow, 2003, Roulston, 2010).

5.5. Ethical principles

Any research that includes participants, including vulnerable groups, requires an awareness of ethical principles (Orb et al., 2001). Prior to collecting data, obtaining the permission of Research Ethics Committee (REC) is a key activity that allows researchers to carry out a study (Creswell and Poth, 2018). The purpose of such an activity is to safeguard the rights and welfare of research subjects (Polit and Beck, 2008).

This study followed four common ethical principles, including autonomy, justice, beneficence and non-maleficence. Six potential ethical issues, including voluntary participation, informed consent, confidentiality, data management, the relationship between participants and researchers, and dissemination of the findings, were taken into account and delineated in the consent forms (**Appendix 4**) (Orb et al., 2001, Polit and Beck, 2008, Pollock, 2012).

During study recruitment, participants were introduced to me by health professionals and social workers in the hospital and NGOs (**Section 5.6.5.**). There is a real value working with gatekeepers, particularly when studies

involve vulnerable groups, where gatekeepers' close relationships with and knowledge of prospective participants can ensure that appropriate approaches are made (Ritchie and Lewis, 2014). In respect of participants' autonomy, prospective participants were informed of the purposes and procedure of the study along with a written notice, and were given one or two weeks to think if they would like to take part in this study. Taking part in this research was completely voluntary, and thus prospective participants were informed that they could refuse to participate or withdraw at any time without penalty.

Justice places an emphasis on treating participants equally unless there is an ethical justification for treating them differently (Gostin, 1991). In thinking about justice towards study participants, this study ensured that HIV-positive drug users were selected as equitably as possible and recruited based on the factors that were clearly relevant to this study (**Section 5.6.5: Sampling method**).

In accordance with the principles of non-maleficence and beneficence which emphasise 'do-no-harm' and benefits to participants (Orb et al., 2001; Pollock, 2012), prospective participants were informed that this research would not bring direct benefits to participants but indirect benefits, such as contribution to society's knowledge. They were reassured about the confidentiality of their responses and identity. However, there was a limit to confidentiality due to the concerns over participants' disclosure of the information that was related to harms to others. In an attempt to prevent participants and others from harms and ethical dilemmas, participants were informed to not disclose any instances of harm to other people or illegal activity for which they have not already been convicted. In doing so, it allowed participants to have some control of agenda and prevent over-disclosure. During interviews, participants were treated in a non-judgmental and confidential manner with dignity, respect and justice (Mamotte, 2012). If any issue occurs during interviews, such as psychological distress, prospective subjects would be informed that I would be in the position to be a

listener and to provide referrals to appropriate services (Mamotte, 2012). A list of community services was available for them.

When transcribing interview data, participants were given code numbers (Polit and Beck, 2008). The list of participants' names and code numbers were kept separate to protect their anonymity (Grove et al., 2013). During data analysis, I would ensure the findings were developed transparently and grounded from the data. Misinterpretation of the data would lose the value of truly conveying their concerns and voices. Data files were encrypted in the VeraCrypt and participants' informed consents and personal information were kept separately and securely in locked cabinets at the School of Health in Social Science, only available to Szu-Szu Ho (the researcher). According to Information Commissioner's Office, ICO (2018), data can be kept for longer if researchers keep it for public interest archiving, scientific/historic research or statistical purposes. This study is not bound to any funder's policy relating to data retention periods, and thus anonymised digital data will be retained intact by the researcher indefinitely for future research and publication. Hard copies will be destroyed upon the completion of PhD study. Participants were told that findings would be disseminated anonymously through journals and conferences.

Following the detailed explanation of the study information, if participants decided to take part in the study, a copy of the completed consent forms was agreed and retained by both parties. If participants had any questions regarding this research, my contact information was provided in the informed consent form.

Having gone through the review of research ethics committees of a medical centre in Taiwan and the University of Edinburgh, this study was approved and data were collected at the hospital and NGO settings over the period between 09/10/2015 and 09/10/2016.

5.6. Recruitment and sampling

5.6.1. Sample— Inclusion and exclusion criteria

The following criteria were used to identify suitable participants and meet the research aims.

Table 3: Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Individuals are eligible to participate in the study if they are: 1) HIV-positive 2) at least 20 years old (individuals under 20 are under the care of a legal guardian) 3) able to complete the interviews in Mandarin 4) illicit drug users (current and past) 5) have been on HAART regimens	Individuals are not eligible if they are: 1) HIV-negative 2) less than 20 years old 3) not illicit drug users 4) currently hospitalised or in prison 6) unable to give informed consent 7) not on HAART

In an attempt to understand HIV-positive drug users' medication adherence behaviours, affected individuals who were hospitalised and in prison were not included because their HAART medications were administered by nurses instead of themselves.

5.6.2. Study settings

HIV-positive drug users were recruited from three sites, HIV outpatient settings at a hospital, an HIV association, and addiction support association in Taiwan.

The medical centre is a largest and renowned referral hospital in the capital city of Taiwan, which provides comprehensive services for people with HIV. Patients attend their routine consultation every 3-4 months. I recruited participants at this site due to my connection with the HIV specialists in the hospital. The HIV association and addiction support association are the largest HIV and addiction support associations in Taiwan where drug users with HIV are mainly referred. The HIV association is an NGO, which provides a range of HIV services, including temporary housing, outreach services, counselling, referrals, social activities, and support groups for HIV-positive

individuals and their families. Services are run by a team of social workers in the central and northern city of Taiwan. The addiction support association is also an NGO, which is operated to help illicit drug users to have the correct concept of health, and to provide them with housing, emotional and spiritual support. The addiction association provided support to drug users, which is operated across Taiwan.

5.6.3. Access to study sites

Taiwan is considered as a highly collective and hierarchical society (Zhang et al., 2005). Such collectivism and hierarchy had an impact on facilitating and limiting access to study sites. Due to the requirements of Taiwan research ethics, finding a clinical supervisor was part of the research process. However, the limited number of physicians I know at the hospital increased the challenge of finding a clinical supervisor. Firstly, I invited Doctor A, who I have known for years, to be the clinical supervisor of this project. Yet, he was not able to be the clinical supervisor. The reason he gave was that he did not have many heterosexual HIV-positive intravenous drug users but MSM. However, he was willing to introduce another physician to me (Doctor B). Doctor B is specialised in infectious diseases and is a deputy director of Department of Internal Medicine at the hospital. Through the introduction of Doctor A, Doctor B agreed to be the clinical supervisor after going through my CV, research proposal, and supporting documents. In addition, Doctor B introduced me to an HIV nurse specialist, asked her to assist me in recruiting participants, and the HIV nurse specialist agreed to help me.

After the clinical supervisor was confirmed, I started to negotiate with managers at addiction and HIV associations. I firstly introduced myself and the study to them, told them that this study was supported by Doctor B and the HIV nurse specialist, and it would go through ethics committees for research ethics review at the University of Edinburgh and the hospital. The managers permitted that I could recruit participants at their associations (**Section 5.6.2.**).

Given the context described above, it shows that I have employed social networking strategies to gain support and access to research sites. In the Taiwanese society, there is an emphasis placed on interpersonal harmony and hierarchical relations (Su et al., 2012, Zhang et al., 2005). Through the Doctor A's introduction about me to Doctor B, Doctor B appeared to be more likely to take into account of being a clinical supervisor of this study concerning his relationship with Doctor A. Doctor B is experienced and renowned in Taiwan, and the managers at the associations acknowledged him. With Doctor B's support, the managers appeared to trust me, and thus allowed me to recruit participants at the associations. And the HIV nurse specialist was willing to help me to recruit participants due to her relationship with Doctor B. This implies that the use of interpersonal skills can facilitate approaching people with 'the power of authority'. In turn, people with 'the power of authority' were more likely to carefully consider if they wanted to support this study. In addition, it was a reciprocal relation. For example, the managers of the HIV association and HIV specialist invited me to deliver workshops for social workers and nurses. I also travelled to an addiction association in Southern Taiwan to deliver a workshop regarding HAART taking for HIV-positive drug users after my data collection there. Taken together, the chain of social relations was built through the process of constant negotiation and interaction with people, resulting in gaining access to study sites.

5.6.4. Sampling method— adapted theoretical sampling

Glaser and Strauss (1967) define theoretical sampling as the process of data collection for generating theory whereby ideas about the data are examined to explicate categories and concepts. In other words, sampling decisions should be guided by emerging gaps identified from previous coding (Charmaz, 2014, Glaser and Strauss, 1967, Strauss and Corbin, 1998). In contrast to Glaser and Strauss (1967) and Corbin and Strauss (2008), Charmaz (2014) places an emphasis on the concurrent use of abductive reasoning and theoretical sampling until theoretical saturation is reached. Though I mainly drew on Charmaz' approach (2014), I did not use abductive

reasoning in theoretical sampling concerning the amount of time I, as an international student, would have had to invest in the fieldwork (**Section 5.4.3.**). Therefore, the adapted theoretical sampling here is similar to Charmaz's notion (2014) but without the use of abductive reasoning. As a consequence, theoretical saturation (**Section 5.8.5.**) was not confirmed during data collection and preliminary data analysis but after data collection, the full and detailed data analysis, and the review of theoretical literature.

During the process of data collection, I drew on theoretical sampling techniques of collecting, coding, and analysing data, and deciding which data to collect next and where to find them. These techniques used allowed me to learn more about how the process developed and changed, and further help to develop a conceptual model as it emerged. Both theoretical sampling and purposeful sampling are regarded by Morse (1991) as being synonymous where researchers select participants according to study needs.

The sampling methods for this study started with convenient sampling to explore participants' experiences and to lead me to establish sampling criteria for people, situations and settings (Charmaz, 2014, Oktay, 2012). Once obtaining data and constructing tentative ideas about the data through constant comparison and memo writing, adapted theoretical sampling was used to fill incomplete categories and gaps (Charmaz, 2014, Glaser and Strauss, 1967, Strauss and Corbin, 1998). At a later stage, this adapted theoretical sampling also helped to find links among categories (Charmaz, 2014).

While implementing the sampling strategy in this study, a large proportion of HIV-positive MSM who use drugs was not anticipated. Before starting the recruitment, I presumed HIV-positive drug users in Taiwan were mainly intravenous drug users concerning the HIV transmission route. However, during the sampling process, I became aware that a number of HIV-positive MSM used drugs to enhance sexual stimulation. The number of HIV-positive MSM who use drugs is currently not documented in the government website, whereas at recruitment sites, the majority of HIV-positive drug users I found

were MSM as opposed to IDUs. This led to the difficulty of maximising differences and variations among comparison subgroups while sampling (Glaser and Strauss, 1967). In an attempt to identify the variations and patterns of taking HAART across different subgroups with different treatment and drug-using backgrounds (**Section 5.6.6: Sample description**), and for pragmatic reasons, recruitment strategies (**Section 5.6.5: Recruitment strategies**) were applied resulting in the transition to a purposeful sampling approach. As a result, 22 participants (12 MSM, 7 male IDUs and 3 female IDUs) were proportionally recruited in accordance to the HIV epidemiology in Taiwan (**Section 2.5.2.**).

5.6.5. Recruitment strategies

In an attempt to maximise the chance of recruiting HIV-positive drug users during sampling, two recruitment strategies were applied, recruiting participants through health and social care professionals' introduction of me (n=22), and participants' delivery of this study information to their peers (n=0).

5.6.5.1. Recruiting participants through health and social care professionals

Before starting recruitment, I had a meeting with physicians and HIV nurse specialists at the hospital, and managers (social workers) at the associations individually, discussing my research and the inclusion and exclusion criteria. Physicians and HIV nurse specialists agreed that if they had any cases who met my sampling criteria in outpatient settings they would give the potential participants the information sheets with my contact details on the sheets. If participants agreed to take part, the health professionals would call me. I would come to the outpatient settings and then the health professionals would introduce me to them. I would explain the details of this research to potential participants, and give them time to ask questions. If they were interested in the research and agreed to take part after my explanation of this research and reading the information sheet, I would give them time to think and to decide their most suitable time. In terms of interview places, I would

ask them if they were fine to have an interview in a private room of the hospital library or a meeting room of the hospital wards. All of them agreed and preferred to have an interview at the hospital. It seemed that it provided them with a sense of security if the interviews took place at the hospital. Since I was not sure when HIV-positive drug users came to outpatient services, I stayed at the hospital every weekday waiting for health professionals' calls until the services were finished.

In the addiction support association, the manager firstly introduced me to their staff members. The meetings at the associations involved the manager and staff members (social workers) who closely worked with HIV-positive drug users. In the meetings, I discussed with them my intention to volunteer there and to have prolonged engagement with HIV-positive drug users. However, the social workers told me that the volunteers here only helped out with office work and were less likely to engage with HIV-positive drug users. Social workers said that the only way that I could recruit participants was through them. If they had any cases, they would give the potential participants information sheets and asked them if they would like to take part in this research. If participants agreed to take part, the social workers (or the potential participants) would call me and tell me the potential participants' available times. I would accommodate my schedule to meet participants' schedule. In reality, most participants preferred to be contacted by health or social professionals rather than to contact me directly. The reason was that they did not want to disclose their contact number, and were afraid that it could be a catch, or the police would trace the phone number to find them. For these reasons, whether to fill in contact information in the consent forms was optional. None of the participants left their contact information on the consent form.

5.6.5.2. Recruiting prospective participants through participants' referrals

In the fieldwork, I asked participants if they could deliver study information to their peers who met the sampling criteria. This recruitment strategy is called

snowball sampling wherein a study sample is yielded through referrals made by individuals who possess similar characteristics (Biernacki and Waldorf, 1981). However, the strategy of recruiting participants through participants' referrals was challenging. Most participants were mainly concerned about their own privacy, and few were keen to carry this extra task. There were two participants stating that they could ask their peers if they wanted to take part in this study. If their peers would like to take part, they would contact me via the health or social professionals. However, either their peers rejected to take part or I did not hear any news from the participants.

5.6.5.3. Ethical issues encountered during study recruitment

During study recruitment, it seemed that some participants' willingness to participate in this study were due to their desire to please health professionals instead of their true interest in this study. This question arose because some participants (P2 and P16) quickly agreed to take part in this study and wanted to have the interview on the same day of recruitment. For example, during the interview, P2 appeared to be suspicious and did not want to answer some of the interview questions. I had a hard time to deeply explore P2's experience with HAART and drug taking, because P2 had set the boundary between him and me. However, P2 articulated his thankfulness for health professionals' support. P2's responses during the interview conveyed that participating in this study could be due to his gratefulness of health professionals' support but not his interest.

In the case of P16, he had missed appointments a couple of times, and was hard to reach. One day, P16, finally, came to the doctor and nurse specialist's appointment. In our first meeting, he articulated that "*Of course, no problem. You* [HIV specialist] *have given me so much support. Yes.* (Field notes, P16, male heterosexual, 42y, 3/4/2016)" Due to his preference to have an interview on the same day, the interview took place on the day of explaining the research information with the information sheet. In addition to his prompt agreement, there was another sign that might imply his disinterest in this research. During the interview, there were technical and time issues.

The storage of the recorder was full and some interview data were not recorded. Thus, I asked him if I could arrange a second meeting with him. P16 agreed and said no problem, but he did not show up for the next arranged meeting. Fortunately, I usually started transcribing the interview data and wrote memos right after the interview. P16 was open to sharing his experience with HAART and drug taking during the interview, whereas he wore his hat and surgical mask throughout the interview to cover his face. It seemed that he did not want to be recognised, and having a mask on seemed to give him a sense of security. Though there was no tension or distressing moments in the interview, his actions pertaining to missing the next arranged meeting might indicate that his participation in this study was not in accordance with his interest or free will. Rather, his agreement was due to his trust and thankfulness for health professionals' support.

By and large, recruiting HIV-positive drug users and gaining their trust were not an easy task in this study. Ethically, it is advised to let HIV-positive drug users freely and happily agree to take part in a study and without pressure (Orb et al., 2001, Pollock, 2012). In this study, the strategy of recruiting participants through gatekeepers' introduction might have already given participants feelings of obligation to participate in this study due to participants' trust and grateful feeling towards health and social care professionals. In addition, it could also be owing to the emphasis of social relations in the Taiwanese society. As such, a good relationship with health professionals might make participants feel the difficulty in rejecting the invitation, and compelled to participate. However, there are some missing cases in this study, which means that people were able to make their own decision of not participating (**Table 4**).

Table 4: List of non-participation cases

Missing Case	Reason
1	Missing appointments
2 (Coupled with 3)	Not coming to the appointment

3 (Coupled with 2)	Show up in the outpatient setting unexpectedly and left quickly
4	Hospitalisation, and low CD4 cell count
5 (Coupled with 6)	Could not reach her
6 (Coupled with 5)	Could not reach him

5.6.6. Sample description

The introduction of sample description here is to demonstrate how the sampling decisions were framed and how the study sample was distributed. The purpose of this purposive sampling strategy was to obtain data to help explicate the categories in this study (Charmaz, 2014, Strauss and Corbin, 1988). As data collection and analysis progressed, four characteristics of the participants were identified to influence their HAART-taking behaviour, and thus were taken into account for framing sampling decisions: Transmission route, drug-using dynamics, gender, and length of being HIV positive and on HAART.

Table 5: Summary of HIV-positive drug-using participants (Details of socio-demographic information are in Appendix 1)

Participant	Sexual orientation	Transmission route	Type of drugs used	The frequency of using drugs	Length of being diagnosed with HIV	Length of using HAART
P1	MSM	Homosexual contact	Amphetamine, Ecstacy	4-6 times/week	4	4
P2	MSM	Homosexual contact	Amphetamine, Ecstacy	Once/week	6-7 years	6-7 years
P3	MSM	Homosexual contact	Amphetamine, MDMA,	2-3 times/week	6-7 years	6-7 years

			Ketamine, Marijuana			
P4	MSM	Homosexual contact	Amphetamine, MDMA	4-6 times/week	3-4 years	2 years
P5	Male heterosexual	Sharing injecting equipment	Heroin, Amphetamine	>10 times/day	8 years	2 years
P6	MSM	Homosexual contact	Heroin, Ketamine, Amphetamine	>7 times/week	16 years	15 years
P7	Male bisexual	Homosexual contact	Amphetamine, MDMA	1-3 times/month	5-6 years	5-6 years
P8	Male heterosexual	Sharing injecting equipment	Heroin, Marijuana, Amphetamine, Opioid, Cocaine	>10 times/day	11 years	10 years
P9	MSM	Homosexual contact	Amphetamine, MDMA, Ketamine	5 years	7 years	3 years
P10	Female heterosexual	Sharing injecting equipment	Heroin, Amphetamine, MMA, Marijuana	>10 times/day	10 years	5 years
P11	MSM	Homosexual contact	Amphetamine, Ketamine, MDMA, Marijuana	1 time/week	4 years	4 years
P12	MSM	Homosexual contact	Amphetamine, MDMA	1 time/week	2 years	2 years
P13	MSM	Homosexual contact	MDMA, Ketamine, Marijuana, Amphetamine	MDMA: once/week; Ketamine: 4-6 times/day	6-7years	3 years

P14	MSM	Homosexual contact	MDMA, Ketamine, Amphetamine	MDMA: 3 times/month); Ketamine: 4-5 times/day	6 years	4 years
P15	Male heterosexual	Sharing injecting equipment	Heroin, Amphetamine	>10 times/day	9 years	7 years
P16	Male heterosexual	Sharing injecting equipment	Heroin, Amphetamine, Cocaine MDMA	3-4 times/day	10 years	Started it 3-4 years ago (Have taken for three years) -> treatment interruption -> Restarted 1 year ago (have taken for one year)
P17	Male heterosexual	Through contaminated tattoo needles.	Heroin, Amphetamine	15 times/day	13 years	5 years

P18	Female heterosexual	Sharing injecting equipment	Heroin Amphetamine	5-6 times/day	8 years	10 months from her previous pregnancy. Now treatment interruption
P19	Male heterosexual	Sharing injecting equipment	Heroin, Amphetamine	2-6 times/day	8 years	10 months
P20	Female heterosexual	Sharing injecting equipment	Heroin, Amphetamine, Ketamine, MDMA	2-10 times/day	12 years	3 years
P21	MSM	Homosexual contact	Amphetamine, Marijuana, Cocaine, MDMA	Everyday	2 months	2 months
P22	Male heterosexual	Sharing injecting equipment	Heroin, Amphetamine	2 times/day	12 years	1 year

5.6.6.1. Transmission route

In this study, the sample consists of 22 HIV-positive drug users, aged between 26 and 53. Of these, 12 participants were infected with HIV through homosexual contact, and 10 participants were infected with HIV through using contaminated injecting equipment (**Table 5**). The 12 participants who were infected with HIV through homosexual contact had a history of engaging in chemsex. The 10 participants who were infected with HIV through contaminated injecting equipment were heterosexual injecting drug users.

I recognised the difference in subculture between HIV-positive MSM who use drugs and HIV-positive heterosexual drug users. HIV-positive MSM who used drugs in this study tended to engage in chemsex, with the use of Amphetamine, MDMA, and Ketamine (**Table 5**). Recreational drugs were used by participants to enhance sex. On the other hand, HIV-positive heterosexual drug users in this study tended to use heroin, and all of them have committed crimes, such as robbery, murder, sex trade, drug dealing, or illegal gambling. Having identified the difference in subculture between the two groups, I was particularly aware of the importance of sampling the two groups to understand their experiences of taking HAART.

5.6.6.2. Drug-using dynamics

Table 5 shows that all of the participants were polydrug users, which means they used more than one type of drugs at the same time and/or different times. Considering that their drug use tended to be fluid and dynamic, it made it difficult to document how long they have been taking illicit drugs, Moreover, participants did not generally fall into the category of current or past drug users. In that sense, to understand and gain insight into their experiences of drug taking is more likely to capture participants' drug using dynamics than simply classify them as current or past drug users.

By looking at the routes of drug use across the participants, it was revealed in social demographic information that heterosexual HIV-positive drug users were more likely to inject heroin, whereas homosexual HIV-positive drug users were more likely to choose the non-injection routes of drug use. Heterosexual HIV-positive drug users appeared to have a higher frequency of drug use in comparison with the homosexual group. Most heterosexual HIV-positive drug users used heroin for more than 10-15 times/per day, whilst HIV-positive MSM tended to use amphetamine and MDMA for 1-6 times/week or month, or Ketamine for 4-6 times/day. In terms of withdrawal symptoms, all of the heterosexual HIV-positive drug users reported they had experienced severe heroin withdrawal symptoms, but homosexual drug users were more likely to experience psychological dependence, such as anxiety

and craving for sensational stimulation. The severe addictive effects of heroin were described by participants as making it harder for them to quit heroin, forming a circular process of injecting heroin, feeling happy, experiencing withdrawals, finding money or committing crimes to get money, buying expensive heroin, and injecting heroin to get fixed. Due to the nature of severe addictive effects of heroin and engagement of illegal activities, I found that heterosexual active IDUs were more hidden, which led to the challenge of recruiting them. In summary, the drug using dynamics between heterosexual and homosexual groups are quite different and can influence participants' HAART-taking behaviour. Thus, their illicit drug use was framed into my sampling decisions.

5.6.6.3. Gender

Of the 22 participants, 11 were MSM, 7 male heterosexuals, 3 female heterosexuals, and 1 male bisexual. While sampling, I encountered the difficulty of finding female HIV-positive drug users. One issue was addressed by nurse specialists at the hospital and staff members at addiction support association. That is, there was a lack of addiction support services tailored for female HIV-positive drug users. The support services in the addiction support association, where I recruited participants, were mainly for male and female drug users and male HIV-positive drug users. Another issue brought up by social workers at the HIV association was the low number of female HIV-positive drug users who accessed care. Such low number causes the difficulty of running support services for this group. As documented in the CDC (2017), there were reported 917 female HIV cases across Taiwan, which could include those in jail, those not receiving HAART, and those not in the hospital or associations where I recruited participants. In addition, concerned about the nature of illegal drug users and social expectation of being female in Taiwan, it might also have led to the difficulty of recruiting female HIV-positive drug users. Non-participation cases are in **Table 4**.

5.6.6.4. Length of being HIV positive and on HAART

Among the participants, the length of being diagnosed with HIV ranged from 2 months to 16 years, and the length of being on HAART ranged from 2 months to 15 years. Participants had a time gap between being diagnosed with HIV and being on HAART, ranging from 1 year to 11 years. By comparing the time gap between being diagnosed with HIV and on HAART across participants, it was revealed that heterosexual HIV-positive IDUs were more likely to delay their treatment as opposed to homosexual HIV-positive drug users. Eight out of the 10 heterosexual participants had a more than 5-year gap compared to 2 out of the 12 homosexual participants who had a more than 3-year gap. Of the 8 heterosexual participants, 1 had treatment interruption for around 3 years, and another received HAART before but was currently having treatment interruption. It could be argued that heterosexual group's delayed access to care is linked to their addiction to heroin and engagement of illegal activities.

5.7. Data collection

5.7.1. Voices of vulnerable groups in qualitative inquiry

The WHO (2013) has sought to promote active involvement of HIV-positive individuals in health and social care. This policy background is often accompanied by growing attention of social injustice for people living with HIV (Henrickson and Fouché, 2017). Although levels of vulnerability and marginalisation may vary from culture to culture, people living with HIV are generally considered both marginalised and vulnerable (Henrickson and Fouché, 2017). In people labelled marginalised or vulnerable, they tend to struggle to find a voice with which to speak in the public realm (Fisher, 2012, and Henrickson and Fouché, 2017). When not exercising the rights to seek social justice, the voices of the individuals can be silenced (Li, 2004). Silence is defined as an absence or inadequacy of language to express in life (Hedges and Fishkin, 1994). Such silence is affected by social positions and vulnerable people's attendant cultural taboos and anxieties, and as a result

silence becomes their coping approach in many circumstances (Fisher, 2012, Hedges and Fishkin, 1994, Li, 2004). Without recognising vulnerable and silenced people's agency to speak for themselves, a liberating effort to reclaim their silenced voices may become groundless (Li, 2004). Qualitative research can serve as a means for marginalised people to voice (Bryman, 2012, Denzin and Lincoln, 2011, Fisher, 2012). Through qualitative inquiry, it can contribute to marginalised people' visibility in the public sphere, and thereby provide a forum for their voices that can inform social and political debates (Fisher, 2012).

5.7.2. Face-to-face in-depth semi-structured interviews

To elicit multiple meanings relies on the use of language and communication (Berger and Luckmann, 1966, Charmaz, 2014). Thus, interview was chosen in this study to understand HIV-positive drug users' experiences of taking HAART, to unfold the meaning of their experiences, and to uncover their lived world. Creswell and Poth (2018) defined an interview as a social interaction based on conversation. In this study, data were collected by using face-to-face semi-structured in-depth interviews. A face-to-face interview was for the researcher and the researched being physically located in the same private room and talking face-to-face (Creswell and Poth, 2018). To deeply understand participants' experiences of HAART taking and their lived world, the discussion with participants during the interviews involved their experiences of being HIV positive, taking HAART, and illicit drug use, all of which tended to be sensitive topics. As such, concerning participants' confidentiality and the sensitive issues being raised during interviews, face-to-face interviews provided a more private and secure space for participants to share their personal experience as opposed to focus groups (Grove et al., 2013).

The in-depth semi-structured interviews are exploratory and at the same time offer depth through probing (Creswell and Poth, 2018). Probing techniques were used to further explore participants' experiences of taking HAART by adding and/or changing interview questions (Ritchie and Lewis, 2003). In this

study, interview questions were open-ended, general, and focused on the central phenomenon relating to HIV, HAART taking, and illicit drug use. As the interview progressed, the interview questions were revised or added to depending on participants' answer to the questions, and interview situations observed. These approaches helped me to deeply explore participants' experiences of taking HAART, to clarify any relevant issues raised by respondents, and to fill the knowledge gaps identified during the data collection and analysis process (Barriball and While, 1994, Charmaz, 2014, Elmir et al., 2011).

In addition, this approach provided interactive opportunities between participants and me, helping to establish a sense of rapport with HIV-affected drug users and to reduce the likelihood of obtaining socially desirable answers (Barriball and While, 1994, Elmir et al., 2011). For example, P9, at the beginning of the interview, appeared to open up less and share less of his personal experience of how he was infected with HIV. Initially, he said

> "*I protected myself very well while engaging in sex, but I do not know how it happened. It has happened, and thus I would just accept this truth of being HIV positive*." (P9, MSM, 35y)

Once P9 trusted me as the interview progressed, P9 gradually opened up.

> Interviewer: "*What do you mean by it? Sorry, I don't understand. Could you tell me more about it.*"
>
> "*Actually, one time my drink was spiked. I went meet one online friend. He gave me a drink. After drinking it, I felt sleepy and hot. I was innocent and did not know it would happen. I knew it after the incident.*" (P9, MSM, 35y)

Drawing on the research experience, it indicates that knowledge was constructed through the interaction and constant negotiation between participants and me. Rephrasing interview questions and restating participants' answers were used in the interviews for clarification. Such

technique was also used in the interview with P2, as he sometimes appeared to hold words back and was not sure how to answer. When rephrasing questions in a different way, P2 could continue with additional content.

Together, by using the one-on-one in-depth semi-structured interviews, it allowed me to explore participants' experiences deeply, and to reach a level of shared understandings that would permit relevant and adequate responses (Mishler, 1991). In this study, the length of in-depth interviews ranged from 1 hour to 2 hours.

5.7.3. Interview guide

An in-depth interview is based on the ability of the researcher to establish a good rapport with participants (Denzin and Lincoln, 2018). A good rapport with participants is achieved where the researcher can seek to put participants at ease and create a climate of trust (Ritchie and Lewis, 2003). This involves being able to demonstrate interest, respect, understanding, and sympathy (Doody and Noonan, 2013, Elmir et al., 2011). In this study, the stories participants shared with me were often quite sensitive, and some participants tended to be shy and less articulate. Thus, my task was to ease them and make them feel comfortable throughout the interview process. The beginning of the interviews was designed to have a conversation with participants in an informal way, such as "*How are you?*"

Once opening up the conversation with participants, I started to collect participants' socio-demographic background (**Appendix 5**). Collecting background information at the beginning provided me with an opportunity to collect important context information and questions formation for the following in-depth interviews. When collecting socio-demographic information, it was done without digital recording with the aim to set the scene of the interviews in which participants could get to familiarise with me and build trust and rapport. Once participants seemed comfortable with the interview process, and collecting background information was complete, the in-depth interviews with digital recording commenced.

The aim of the in-depth interviews was to achieve the breadth and depth of participants' experiences of taking HAART. During the interviews, I, initially, asked broader and more general questions (**Appendix 6**), such as "*Please tell me your experience of living with HIV*", "*Please describe your experience of using drugs*", and "*Please tell me your experience of taking HAART*". Following these broad questions, probing was used to focus on the breadth and depth of coverage across and within the research topic. The follow-up questions I asked in the interviews depended on participants' answer (Ritchie and Lewis, 2003). However, there are basic principles I applied in the interviews. In probing, two types of questions were yielded— content mapping and content mining questions. Content mapping questions were used to open up research territory and identify the dimensions that are relevant to participants' experience of being HIV, taking HAART, and drug use (Ritchie and Lewis, 2003). In the interviews, this type of questions involved what, process, extent, changes in perception, perspective, and HAART-taking, or understanding the contexts, such as " *What makes you think that HIV is horrific*", "*How about now? Has your perception of HIV and cocktail therapy changed over time?* [Both Cocktail therapy/treatment and HAART are often used interchangeably among Taiwanese people]", "*How has the cocktail therapy* (or drug use or HIV) *influenced your life?*", "*Tell me about your family*", "*What impeded and facilitated your medication-taking?*", or "*Earlier in the interview, you told me you have been diagnosed with HIV for 11 years but you have taken the treatment for only 1 year. Tell me more about it and what affected your decision to receive and not receive the treatment*".

Content mining questions were used in this study to explore the depth of participants' stories (exploratory and explanatory probes) and to clarify the meaning of terms used by participants (clarificatory probes) (Ritchie and Lewis, 2003). These type of questions in the interviews involved probing for reasons, consequences of actions, and underlying meanings constructed by participants, such as "*What does cocktail medications mean to you?*", "*Why do you think illicit drugs (cocktail medications) are important to you?*", "*Tell*

me how living with HIV (and the treatment) has affected you", or "*Earlier you told me that using amphetamine has greatly affected your medication-taking over the last 3-6 months, whereas you have used this type of drugs for a year. Why did not amphetamine affect your medication taking in the first 6 months of using it?*" By asking these type of questions, it not only helped me to obtain a full description and understanding of participants' experiences of taking HAART but assisted in challenging inconsistency in participants' account and minimising my taken-for-granted assumptions.

The ending questions were used to bring participants back to a normal conversational level, and left them feeling positive about this interview (Charmaz, 2014, Ritchie and Lewis, 2003). Examples of the ending questions used in the interviews were "*Is there anything else you want to share with me and let me know?*", "*Based on the experiences you shared with me, do you have any advice?*", and "*Do you have any question you want to ask me?*".

5.7.4. Environment and timing of interviews

Interviews were conducted at the time most convenient for participants and in places that were agreed by both participants and the researcher and free from interruptions (Elmir et al., 2011, Doody and Noonan, 2013). There is an agreement in the literature that care should be taken to create interview environments as comfortable as possible (Creswell and Poth, 2018, Ritchie and Lewis, 2003). In this study, interviews were taken place at a meeting or conference room at the hospital library, associations, or inpatient wards. These rooms were quiet and private. Though the options of these rooms were given to participants, they were not restricted to have an interview in these rooms. They could choose any public locations where there was a private room, such as public libraries. All of the participants preferred to have their interviews at the hospital or associations due to a sense of security given by these trusting places. Five participants had their interviews in a private room of the hospital library; nine participants were interviewed at a private meeting room on wards; eight participants were interviewed in a private room of the associations. The environment where the interviews took

place at the aforementioned sites was quiet and did not interrupt my interviews with the participants.

During data collection, it was sometimes challenging to find a private room at the hospital, because some rooms were in use or booked by others. I would need to book a room in advance. When participants came to outpatient services unexpectedly and preferred to have the interviews on the same day, I would need to quickly find an available room. At that time, health professionals were supportive and helped me to find a room that was private and quiet. At the associations, social workers would arrange the time and place of interviews for me, and thus I did not encounter difficulty in finding a venue. In terms of the timing of interviews, health professionals and social workers quite protected the privacy of HIV-positive drug users. I could not directly contact potential participants. Instead, I needed to keep in touch with potential participants through health professionals and social workers.

The interviews in this study were digitally recorded for five reasons: 1) helping to correct the natural limitations of my memories, 2) allowing me to examine what participants said more thoroughly, 3) permitting repeated examination of participants' answers, 4) opening up the data to public scrutiny, and 5) identifying the nuances of the conversation, such as voice or tone (Bryman, 2012, Halcomb and Davidson, 2006).

Despite the advantages of recording interviews, I had been concerned about the interview atmosphere. Even though all of the participants agreed that I could record the interviews, the use of a recorder might disconcert participants and increase the challenge of building rapport and gaining trust. In an attempt to build a rapport with participants, I intended to establish a friendlier and less tense interview atmosphere by not recording while asking socio-demographic information and making the conversation ease. Such a decision was made, because recording one's voice while asking close-ended questions with regards illicit drug use might be too intrusive from my viewpoint (e.g. questions on current/past drug user, and types of drug used). The interaction with participants was ongoing over the interview process. To

gain the participants' trust and create a positive impression was considered important, especially at the beginning of the interviews. If participants shared additional information while asking their socio-demographic background, I took notes and explored further later during the interviews. As a consequence, it helped to build the research rapport between participants and me.

5.7.5. The impact of power on accessing data

5.7.5.1. Gaining the trust of participants

This study involved sensitive topics, such as HIV and illegal drug use, which could be potentially challenging to gain HIV-positive drug users' trust and build rapport. In that sense, I was particularly aware of my positionality and the power dynamics during the interviews.

I am positioned by gender, age, educational background, and sexual identity, all of which might have influenced certain insights in the study. However, the complexity of positionalities and power dynamics cannot be explained just by each one of the elements (Merriam et al., 2001, Rose, 1997). These elements are relational and interactive to influence how participants perceived and positioned me (Rose, 1997). Participants, themselves, might weigh each factor differently, subsequently influencing what they wanted to tell me. This resonates with Rose's (1997) notion. That is, each one of the socio-demographic elements is relational, and it is based on "*difference from others but not on separation from others* (Rose, 1997, P.314)." The Taiwanese society values hierarchy and social relations (Su et al., 2012, Zhang et al., 2005). In healthcare settings, health professionals are often respected and viewed as trustworthy by patients. Due to this reason, through health professionals' introduction of me and my nursing background, participants appeared to respect me and were willing to open up themselves. One example from P4 is provided as below:

> Interviewer: "*How did you get out of the drug circle?*"

P4: "*I have deleted everything….It is not easy to tackle the issues that happened in the circle. I feel thankful for having you here, listening to me. Because I cannot disclose these things to others….I don't know where to disclose those things that have been kept deep down in my heart. I know that kind of hopelessness…This is the darkest side of the society. Drugs aren't good. They were given the drugs and couldn't control themselves. Then our laws are enacted to punish them instead of understanding them. No one thinks about it. This society just curbs violence with violence. Some people just wanted to have fun and be happy. They didn't intend to harm others. But indeed there are other people who just want to harm others*."

Memo: In terms of my interaction with him, I could sense that he trusted me by the way he treated me with respect and the amount of information he shared with me. The excerpt — "*I feel thankful for having you here, listening to me.*"— also illustrated his trust in me… By gaining insight into his experience, it strengthens my will and determination of working in the field of drug addiction. Personally, I have never used illicit drugs before and do not have drug friends. In my previous clinical experience, I had never deeply explored their experiences with regard their personal networks. This was new to me. My background made me be a complete outsider of the topic in relation to illicit drug use and gay subculture. This resonates with participants' narrative — "*No one thinks about it.* ". Drawing on P4's statement, "*this society just curbs violence with violence*", it seems that the past me only saw the surface of the problems... (Analytic memos, P4, MSM, 26y, 01/12/2016).

This was one of many examples that participants showed their respect and trust in me. My interactions with participants, over the period from health professionals' introduction of me to interview completion, played some roles in their perception of me and ultimately influenced the depth and breadth of the stories they shared with me. Although my educational background might

have accrued weight to my side of the power equation, I approached the unequal power relations in the research encounter by treating participants with respect and non-judgemental attitude. This helped to create a secure and welcoming environment for them to respond to during interviews. Participants could decide when the interview was held and what information they wanted to share. This was a way of conveying that they are important in this project. In addition, I demonstrated my interest in their stories, and encouraged them to explore further, which showed part of my position as unknown and participants as the knowers. Collectively, such approaches had helped to ease tensions, and build bridges and trusting relations (Marshall and Rossman, 2016).

In addition, my position had emerged gradually, beginning with my roots in constructionism and then adopting feminist standpoints. This allowed vulnerable participants' voices to be heard and assisted in merging scholarship with politics to work against the forces of oppression, which is greatly emphasised by the feminist theory (Denzin and Lincoln, 2018, Mascia-Lees et al., 1989). This resonates with Rose's (1997) notion that "*The researcher holds power, she/he can also give it away. She/He is positioned in power rather than constituted by it* (P.310)." In that regard, it seemed that positionality and power relations are not static, but dynamic and could shift, which required constant negotiation during the research process.

5.7.5.2. Failing to gain the trust of a participant

From my view, it seemed that there was one participant who presented his distrust in me throughout the interview, frequently held back his words, and gave socially desirable answers.

> Memo: ….Sometimes, he would avoid some interview questions and eye contact, especially when asking questions relating to illicit drug use and HAART use. I told him no need to answer the questions if he did not want to. However, I could sense that he had his guard up and did not trust me. Although before the interview he told me that he was fine and did not mind to answer any questions, when the interview started it

> became the other way around. His excerpt— "*I don't want to go back to jail. I am afraid of being caught*"— implies that he tried to protect himself and avoided any possible harm. His suspicion did not only happen in this interview, but before the interview, an HIV specialist told me that P2 sometimes questioned her, asking why she wanted to know it… However, in the interview, P2 told me that the nurse specialist was the biggest supporter and motivator in his life, and he felt thankful for that. In that regard, it seems that his self-protective acts might not necessarily speak for his perception towards the persons (Field notes, P2, MSM, 32y, 25/09/2015).

Drawing on the field notes, it explicitly shows that P2 perceived that this interview might expose him to greater risk. Asking about his illegal drug use and HAART taking is intrusive and potentially exploitative. Concerning confidentiality, it seemed to have led him to feel uncomfortable and insecure about the questions asked pertaining to his HAART taking and drug use, and thus chose to skip answering some of the questions. With his guard up, it blocked the channel of my negotiation with him and the rapport built through it, despite my efforts of gaining his trust and providing information of how his data will be managed. I cannot translate the situation and his response precisely, and I admit my limits to acknowledge and understand his personal locations. In line with my admission of such limited ability to fully understand P2, Merriam et al. (2001), Pillow (2003), and Rose (1997) embraced writing uncertainties into research due to the impossibility of complete translation of knowledge. Because language itself is already a translation from a non-verbal world (Rose, 1997). Reflexivity should be pushed towards the uncomfortable and cannot be just a simple story of participants, subjectivity, and self-indulging telling (Pillow, 2003).

In this study, there were moments of struggling with gaining P2's trust, and understanding him. This has influenced how I could deeply explore his experience. To address such issues, some scholars classified researchers into two types of roles in an attempt to distinguish the difference in each

role's influence on how knowledge is situated— insider and outsider. Being an insider means having a better access to the implicit and introspective meanings of a person/group's experience (Merton, 1978). On the other hand, being an outsider means being more objective, and having the ability to see things that may not be evident to insiders (Merriam et al., 2001). Both insiders and outsiders have their own weaknesses. Insiders are considered to be too close to the culture to identify issues that may have been taken for granted, leading to inherent biases; outsiders were less likely to capture the implicit meanings of the experience participants share (Merriam et al., 2001). In this study, I am equipped with the knowledge of HIV and HAART. Nonetheless, when it comes to participants' personal encounters, I was not able to fully understand what and how they have been through. As such, this might have led to P2's distrust of me.

To sum up, positionality and power relations in the research process can exert an impact on how knowledge is produced and interpreted (Doucet, 2008). In this study, the fieldwork experiences revealed complex power dynamics and multiple positionalities, whereby the relation between participants and I was constantly negotiated in the research process. From my locations, all my understandings become subjectively biased and forged through the interactions within the fields of the power relations. Hence, the task of situating and constructing knowledge is to be reflexive throughout the research process so as to make this study more transparent (Bryman, 2012, Denzin and Lincoln, 2018, England, 1994, Pillow, 2003).

5.8. Data analysis

5.8.1. Transcribing data

Transcribing data is an integral process of the analysis of language data in qualitative research (Lapadat and Lindsay, 1999). Transcribing is defined as "*the process of reproducing spoken words, from a recorded interview, into written text* (Halcomb and Davidson, 2006, p.38)". According to Halcomb and Davidson (2006) and McLellan et al. (2003), the philosophical approaches

used in a study affect the way data are transcribed for the study. This study aims to explore HIV-positive drug users' experiences of taking HAART drawing on constructivist grounded theory approach. Grounded theory approach places a great emphasis on the closeness between the researcher and the text. Therefore, transcription of interview data was used in facilitating data analysis by bringing analysts closer to the data (Halcomb and Davidson, 2006).

I digitally recorded all the interviews and then transcribed the recording verbatim in Mandarin myself, including non-verbal information (such as facial expressions), as soon as possible after interviews were finished. It took about 3 days to transcribe data/per interview. Though transcribing data was time-consuming, it offered great benefits in terms of allowing me to familiarise myself with and get closer to the data (Bryman, 2012, Halcomb and Davidson, 200 6). Given that I have the first-hand knowledge from my involvement in the interview process, I could review my field notes and compared these with transcripts. This allowed me to expand on my impression of the interaction with participants with more considered thoughts and accurate reflection (Lapadat and Lindsay, 1999).

Transcription is a form of interpretation (Poland, 1995 and Mishler, 1991). To ensure the accurate transcripts possible for the analytic process, the recordings were not left behind after transcription was complete. When I wasn't sure about the data, or wanted to recall what was happening during the interviews, I returned to repeatedly listen to the original recordings to assess the adequacy and accuracy of my interpretation of the data (Mishler, 1991).

5.8.2. Translating transcripts

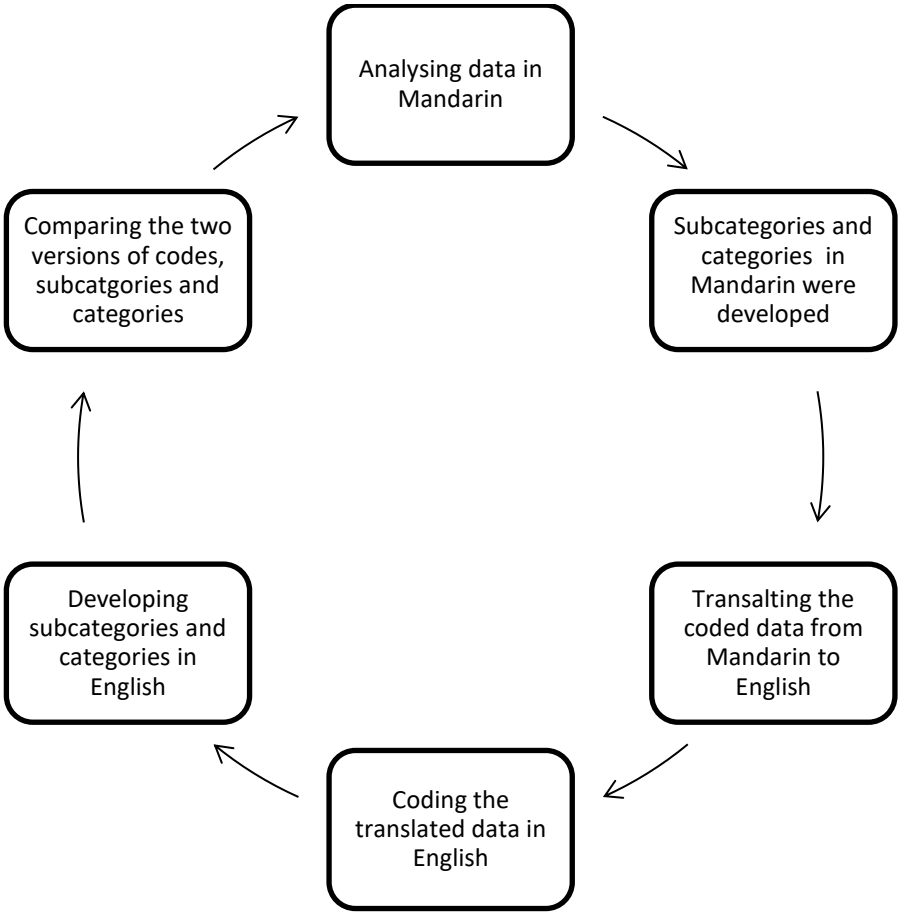


Figure 3: Procedure of analysing data in Mandarin and English

Interpreting the meaning of participant's experience is the core of qualitative research (Esposito, 2001, Mishler, 1991, Polkinghorne, 2005, Riessman, 1993). Nevertheless, researchers do not have the direct access to participant's experience (Polkinghorne, 2005, Riessman, 1993), but instead, we understand the meaning of participant's experience through their language (Berger and Luckmann, 1966). Although language is as a way of understanding participants' experience, meaning shifts to some extent because of participants' limited capacity to recollect their experiences and researchers' involvement in the interpretation of participants' experiences (Polkinghorne, 2005, Riessman, 1993). In that sense, language itself in its essence is already a translation of participants' experiences (Merriam et al., 2001, Polkinghorne, 2005, Riessman, 1993). In the same vein, translation between two different languages also involves interpretation (Van Nes et al.,

2010). The difference in language can generate additional challenges that could hinder the transfer of meanings, and might cause loss of meanings and undermine the credibility of the study (Van Nes et al., 2010).

In reference to current literature, it was suggested to analyse data in an original language as long and as much as possible to avoid potential limitations of understanding the meaning of participant's experience (Chen and Boore, 2010, Van Nes et al., 2010). Taking this advice into account, I analysed the data in Mandarin during the process of data collection and preliminary data analysis. Once sub-categories and categories in Mandarin were developed, I found that translating the developed categories to English remained complex due to a lack of equivalent concepts. In an attempt to develop meaning-based translation, I checked the interpretations by 1) going back to the coded data, 2) translating these data into English, 3) coding the translated data in English, 4) developing subcategories and categories in English, 5) comparing the translated codes, subcategories and categories with the ones in Mandarin version (**Figure 3**). When analysing the translated data, I would go back to check the data in Mandarin to capture the context and ensure the meaning was not lost. While analysing and interpreting translated data, I would think in English and explain in English. On the other hand, while analysing the data in Mandarin, I would think in Mandarin. This assisted in a better understanding of subtle meaning differences and coming to the English wordings that are close to the data in Mandarin. To help find the best wording, I also used dictionaries to understand terms and discussed with supervisors about the suitable terms for naming the codes, subcategories and categories.

During the process of translating data, the challenge I encountered was to convey meaning using equivalent terminology rather than word-for-word translation. Congruently, as noted by Chen and Boore (2010), Esposito (2001), Twinn (1997), and Van Nes et al. (2010), not all concepts and expressions are universal and translatable due to cultural nuances attending the use of translation. One example is presented below.

> “*In the past, I needed to take 4-5 pills at one time. It was **painful**.*” (P9, MSM, 35y)

The direct translation of the Mandarin word, "痛 (Tong)”, into an English word is “painful”. However, “painful” used in Mandarin by P9 implicitly means his feeling of suffering while taking many pills. In that sense, it indicates that word-for-word translation could potentially lead to loss of meaning. Without making sense of the data both in Mandarin and English, the direct translation of codes, subcategories and categories from Mandarin to English may not completely convey the meaning of participant’s experience. With this in mind, I translated the coded data, and looked deeply into the data again, coded the data in English, and then developed subcategories and categories. The full analysis of the original and translated data allowed me to think about the data differently by making sense of the data in both Mandarin and English, developing my analytical thinking, and naming the codes, subcategories, and categories more appropriately.

Another challenge was to translate concepts for which culturally-bound words were used by participants. For example, idioms in Mandarin are often unintelligible without explanation. At school in Taiwan, idioms are learned through the understandings of the historical context from which idioms were born, which are used frequently in a daily life. Without understanding the context, meanings of the idioms cannot be understood by simply looking at the words, because meanings were developed through the context not the words. One example presented below is derived from P9.

> “*Those friends from the drug circle are just nodding acquaintances. You know. One who mixes with vermilion will turn red, one who touches pitch shall be defiled therewith. As long as I can control myself well, I would try to avoid those friends as much as possible*.” (P9, MSM, 35y)

“*One who mixes with vermilion will turn red, one who touches pitch shall be defiled therewith.“* is a Chinese idiom, meaning good companions have good influence while bad ones have a bad influence. This idiom was derived from

an ancient story where a mother who moved to many places in an attempt to find a better learning environment for her son. By directly translating the words of the idiom, it could not convey the meaning explicitly. Therefore, this study placed an emphasis on conveying the meanings represented in the texts rather than marks in the transcripts (Polkinghorne, 2005). Having a proficient understanding of Mandarin and the intimate knowledge of Taiwanese culture facilitated capturing the meanings of participants' experiences.

5.8.3. Analytic techniques – Constant comparison and memoing

In this study, data were analysed by using NVivo software (version 10 and 11). By a means of NVivo, it has made the analytic work more efficient, whereas to deepen the analysis in the research process over time still relied on me to move into and around the data, codes, and memos. In this section, I will introduce the analytic techniques I used during data analysis— constant comparison and memo writing.

Constant comparison involves making comparison between incidents or cases at the property or dimensional level, looking for similarities and differences within data, codes, categories and memos, integrating categories and properties, defining properties of categories, and writing the theory (Charmaz, 2014, Glaser and Strauss, 1967, Strauss and Corbin, 1998). This technique serves to identify gaps within data and to explain variations and patterns (Bitsch, 2005). By doing so, it helps to capture the dynamic flow of events and complex nature of relationships, advancing conceptual understandings of a social phenomenon (Charmaz, 2014, Strauss and Corbin, 1998).

Memo-writing is the pivotal intermediate step in data collection and analysis (Charmaz, 2014, Corbin and Strauss, 2008). During a research process, memo writing offers a space for researchers to actively engage in research data (Charmaz, 2014). The use of memo writing helps to capture the comparisons or connections being made, to crystallise questions and

directions for further investigation, and to provide an immediate illustration of an idea (Charmaz, 2014, Glaser and Strauss, 1967, Strauss and Corbin, 1998).

Throughout this study process, research memos were written to help me to stimulate my thinking, clarify and direct my subsequent coding, and keep engaging in analysis and increase the level of abstraction of my ideas. I wrote memos in informal language and for my personal use rather than for public consumption. The way I wrote memos was based on what I thought worked and made sense for me (Charmaz, 2014). The research memos were sorted by participant number to keep track of what had happened before, during and after each interview (e.g. observation, interaction and incident), questions being raised, decision being made, my reflection on each interview and participant, and my ideas (Birks and Mills, 2011). In that sense, memos can be a source of displaying a written record of reflexivity, allowing me to analyse data reflexively.

Initially, the memos were more tentative and less theoretical. At the later stage of data collection and analysis, the memos tended to be abstract. At the middle and later stage of memo writing, I started to draw some diagrams in an attempt to organise my thoughts of how to sort and integrate codes, categories, and concepts, and to find relations between categories. In terms of memo sorting, I maintained a folder charting the chronological order of my memos. Whenever new contents were added in the memos, those added content were dated.

5.8.4. Coding

Coding is defined by Charmaz (2014) as ”*naming segments of data with a label that simultaneously categorises, summarises, and accounts for each piece of data* (p.111).” Coding should begin with basic description and moves to conceptual ordering and abstracting and then on to theorising (Charmaz, 2014). In this study, I followed Charmaz’s (2014) coding principles when analysing data, which consist of two phases — an initial coding phase and a focused coding phase.

5.8.4.1. Initial coding

An initial phase of coding involves word-by-word coding, line-by-line coding, and coding incident to incident (Thorne, 2000). At this phase, researchers should remain open to all possible directions indicated by the data being read, and coding should remain open and close to the data (Charmaz, 2014). In the initial coding, I stuck closely to the data, and coded everything early in the analysis to see where it took me as I proceeded. Staying open-minded was also employed in the study in an attempt to explore the theoretical possibilities I could discern in the data. Firstly, I started with line-by-line coding, but sometimes directly did segment-by-segment coding or incident-by incident coding depending on the content participants provided. A big chunk of data provided the context, which enabled me to get the essence of what was being said in the data and understand what the underlying issues were. Each chunk of data was examined closely and could contain more than one code (**Table 6**). By looking at a chunk of data, it not only provided the context, but allowed me to make sense of the meanings participants constructed, to see the interrelationship between codes, and how the codes interactively to influence participants' HAART taking behaviour.

Table 6: An example of initial coding from this study

Codes	Data
Complexity of HAART regimen Unwilling to reveal anti-HIV medications Not taking HAART with him Not taking HAART on time	"*My previous regimen was taken twice a day.* ***Different types of medications were taken at different times. When you didn't want to let others know what you are taking, taking medications with you and on time was challenging***." (P9, MSM, 35y)
The complexity of a HAART regimen	"***Some medications need to be taken every 12 hours. It was really***

Took the medications for her baby during pregnancy	***complicated**. **I had taken the treatment until the end of my pregnancy**. After my baby was born, I didn't continue the treatment*." (P10, Female heterosexual, 33y)
The simplicity of a HAART regimen The complexity of a HAART regimen Forgetting The complexity of a HAART regimen	"*I feel thankful that **the medication regimens are more simplified.** In the past, **I needed to take medications twice a day. And this caused me to forget doses** sometimes. Because **the regimen was more complicated. Two pills in the morning, three pills in the evening**.*" (P20, Female heterosexual, 36y)

This line-by-line, segment-by-segment, and incident-by-incident coding facilitated generation of ideas on which I could build. In the case of P9 from the table, he did not want anyone to see his antiretroviral medications, leading to skipping doses. A question was raised as to whether his perception of HIV was linked to his perception of antiretroviral medications, leading to his decision to skip doses. Such a question was prompted during the interview for further exploration and clarification. In addition, it also led to formulating questions for the following interviews or locating the sources of needed data, such as whether there are people who perceive antiretroviral treatment positively, and whether participants' perception of being HIV positive and the treatment changed over time.

Some questions were raised by looking into the context and process in data analysis (Charmaz, 2014, Corbin and Strauss, 2008). These helped to stimulate my thoughts with regards the wide range of possible conditions and consequences that could enter into context. Subsequently, the context gave rise to problems to which individuals could respond by means of actions/interactions/emotions. In addition, I also analysed data for the

process, which is strongly suggested by Charmaz (2014) and Corbin and Strauss (2008). Studying a process fostered my efforts to develop a conceptual model. In addition to ‘context’ and ‘process’, some sensitising concepts identified from existing empirical studies served as tentative tools (rather than definitive concepts) for opening up inquiry (Charmaz, 2014), such as forgetfulness, support, coping, drug use, and side effects. Together, these analytic techniques served as a guide to deepen my analyses and to discover ideas but it did not determine its content (Charmaz, 2014, Corbin and Strauss, 1998 and 2008).

During initial coding, situational maps were drawn to help me provoke analysis of relations among different codes (**Figure 4 and 5**). This type of mapping was developed by Adele Clarke (2005) as an extension of a grounded theory approach. Within a grounded theory approach, the major use of situational maps is to open up the data and interrogate in a fresh way (Clarke, 2005). The organisation and hierarchical outlining of the parent and children codes also gave me a handle on them (**Figure 5**). By virtue of visualising the emerging codes through mapping and linking them, it had stimulated my thinking (Clarke and Charmaz, 2014). Moreover, the codes were named and defined based on the data, whereas these codes did not always stay the same but were renamed and redefined as analysis proceeded.

Memos were written throughout the process of data collection and analysis. When engaging in mapping and coding, I constantly compared data with data, data with codes, data with memos, one incident with another, and one interview with another. This prompted me to keep interacting with data, making sense of participants’ experiences. The analysis in this study was not structured or static, but rather I moved back and forth between data, codes, cases, memos, and sociodemographic information. By looking into HIV-positive drug users’ experiences of taking HAART from different vantage points, making comparisons, following the lead, and building on ideas, my

sensitivity of the research topic had grown to help increase levels of abstraction in data analysis.

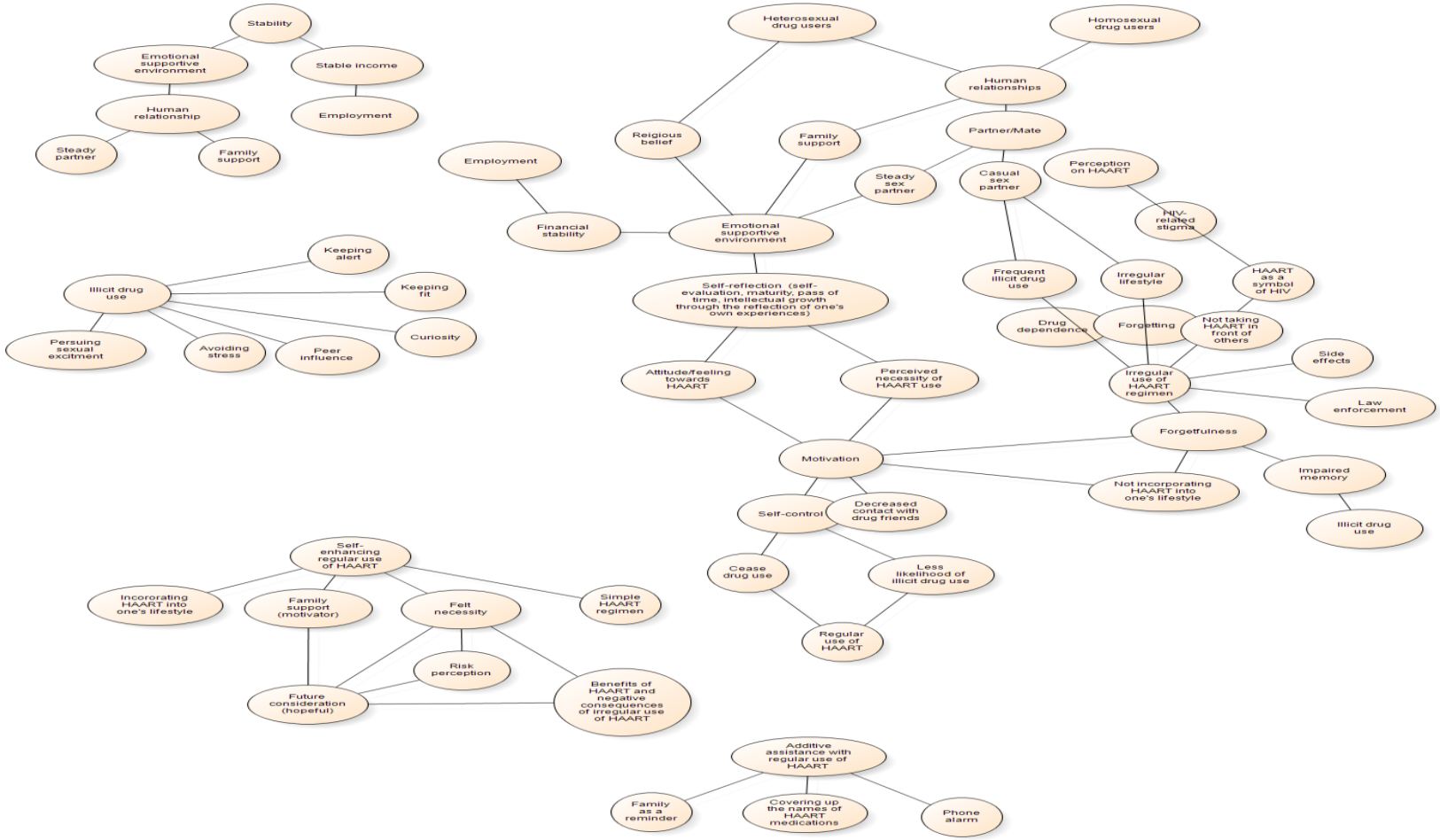


Figure 4: Using modelling function in NVvo to see how the pieces of the puzzle fit together in a variety ways

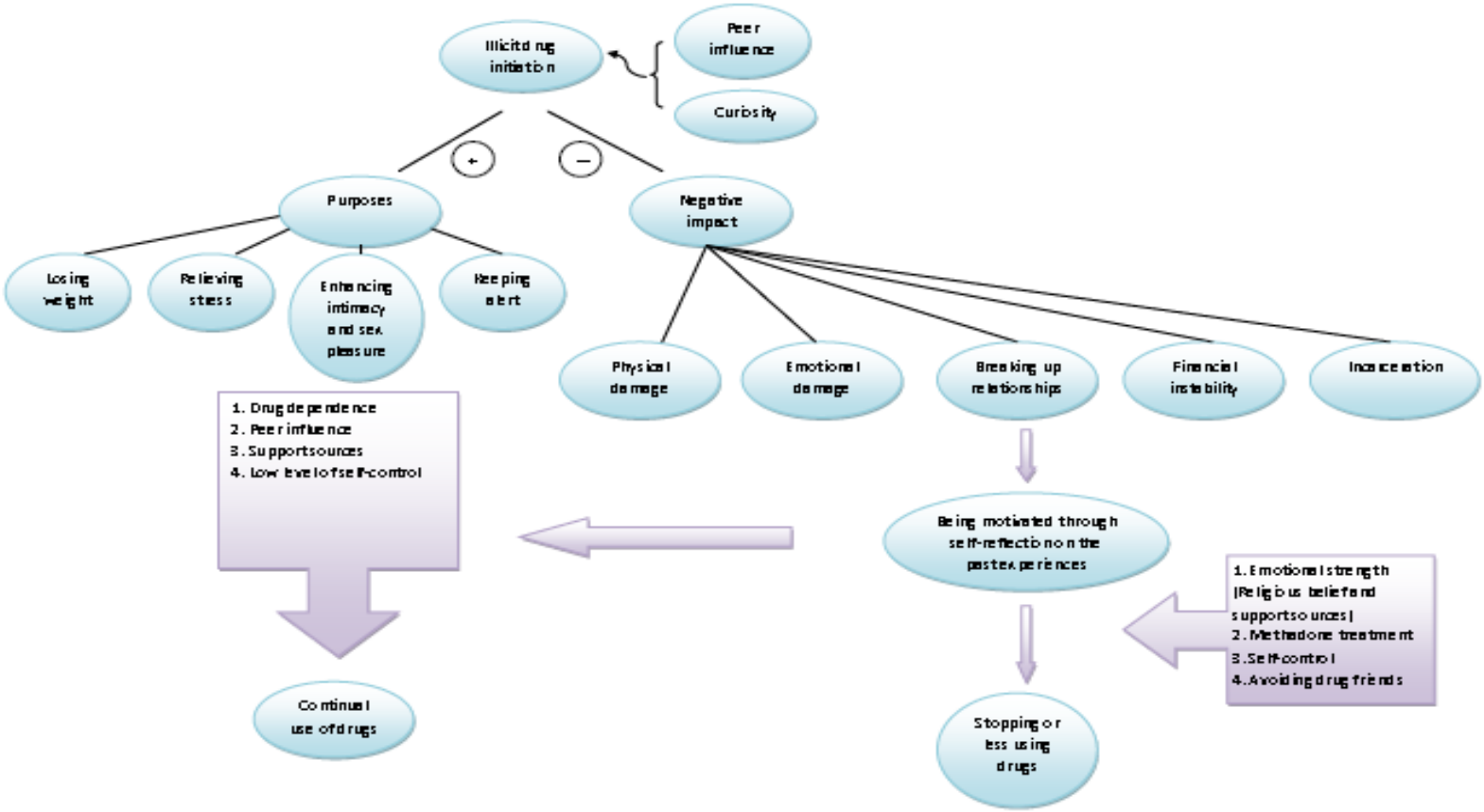


Figure 5: A tree diagram of illicit drug use

5.8.4.2. Focused coding

The focused phase involves using significant or frequent initial codes to synthesize, integrate, and organize large segments of data (Charmaz, 2014, Thorne, 2000). Theoretical integration and formation begin with focused coding and proceeds through the subsequent analytic process (Charmaz, 2014). During focused coding, I used the codes to sort, synthesise, and shift around to analyse the data, grasp ideas from different angles of perception, and make decisions about which initial codes made the most analytic sense to categorise (Charmaz, 2014). Similar codes were assembled together to analyse their commonalities, attributed meanings to the organisation, and then layered my analysis into increasing levels of abstractions from codes, subcategories, categories, to concepts, to the interrelationship of the concepts, and to a larger conceptual model (Saldaña, 2015). These were done by collapsing and expanding categories, adding and deleting some of them.

Social world maps and positional maps were used to help to deepen an understanding of participants' experiences and meanings attached to them. Social worlds maps (**Figure 6**) allowed me to gather my thoughts by locating participant's HARRT-taking behaviour contextually within the range of social, political and health environments and making collective sociological sense (Clarke, 2005, Corbin and Strauss, 2008). In contrast to the ecological Model by Bronfenbrenner (1979) treating various contextual influences as isolated, social worlds maps view the various influences as interactive or collective (Clarke, 2005).

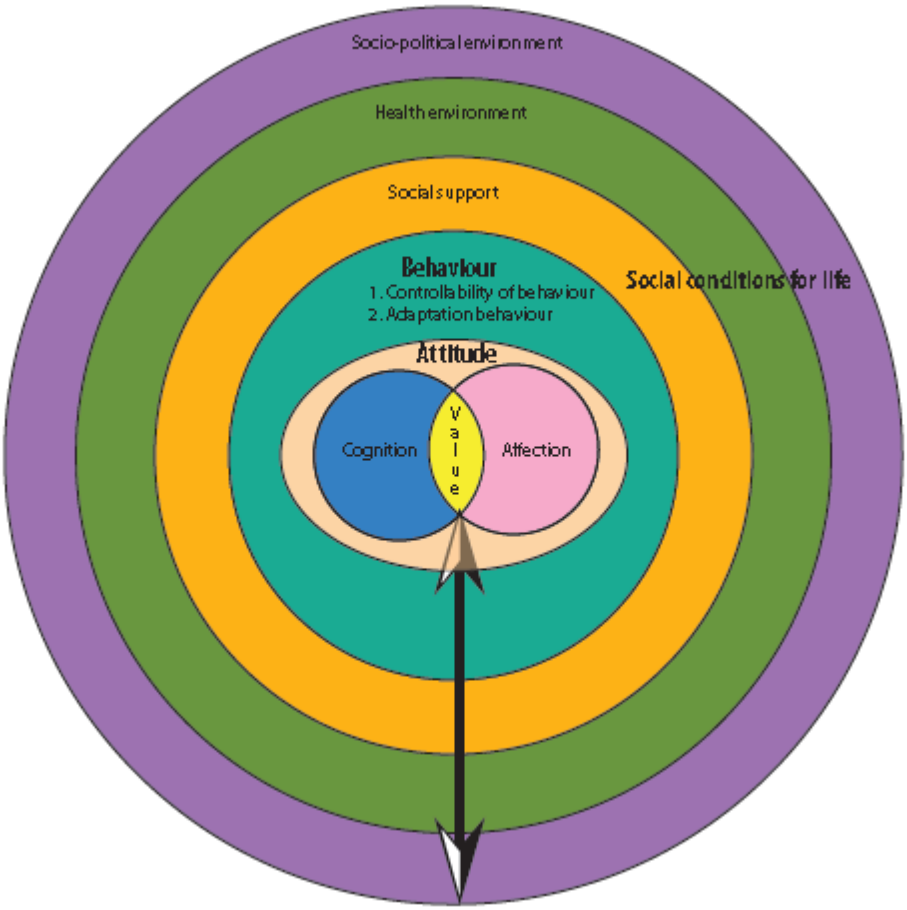


Figure 6: Social worlds map: locating HAART-taking behaviour contextually

Positional maps (**Figure 7**) are particularly helpful when the study topic is very complicated (Clarke, 2005). Positional maps were used frequently to compare case with case, incident with incident, or situations with actions. **Figure 7** is an example which I used to compare case with case with regards length of HAART taking and the regularity of HAART use among participants. The main point of drawing maps or diagrams was to mine the data, dig beneath the surface to discover hidden meanings that are within the data, and identify the patterns (Clarke and Charmaz, 2014).

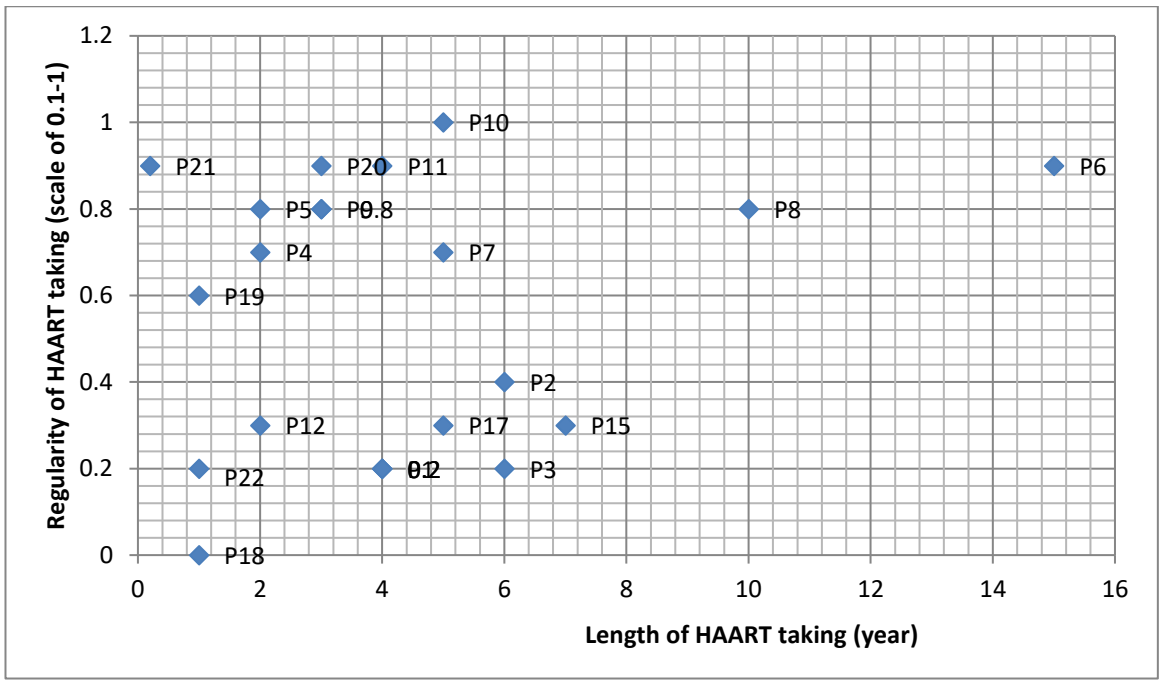


Figure 7: Positional map: Length of HAART taking by its regularity

The diagrams presented above are not finished products, but rather they were part of the analytic journey. In this study, initial coding and focused coding appeared to be a nonlinear process. I went back to re-do initial coding when analysing translated data, which helped me to study participants' experiences afresh. Through continued engagement with data, codes, categories, cases, and memos, my theoretical sensitivity was developed. As analysis progressed, all categories gradually came together and became systematically integrated around the core category. Core category was described by Corbin and Strauss (2008) and Creswell (2013) as having the ability to pull all the other categories together, and the other categories centred around and related to the core category. At an early phase of focused coding, participants' attitude was classified as the core category, whereas during the analysis of translated data, it was revealed that the Mandarin concept "心態 (a combination of heart and attitude)" could not be translated directly into English. Thus, in the end, the core category emerged as a new word, value, that subsumes all of the other categories and without losing the meanings, which is discussed in **Chapter 7**.

Though analytic techniques of grounded theory were used in this study, grounded theory has been criticised for fracturing the data and violating the integrity of participants' narratives (Clarke and Charmaz, 2014). As such, it could lead to eliminating the sequential and structural features that characterise narrative accounts (Clarke and Charmaz, 2014, Riessman, 1993). Nevertheless, grounded theory approaches are mainly used for theorising social action at a collective level (Clarke and Charmaz, 2014). The emphasis of sequential and structural features in narrative analysis does not fit for "*the topics and theories in which the characteristics of actors as active subjects remain unexplored or implicit*" (Riessman, 1993, p.5).

5.8.5. Theoretical saturation

Theoretical saturation refers to no additional data that have been found to develop properties of a category and no theoretical insights that have been found (Charmaz, 2014, Corbin and Strauss, 2008). Reaching saturation should be based on the widest possible data that have been reached in a category (Charmaz, 2014, Corbin and Strauss, 2008). Charmaz (2014) suggested the combined use of theoretical sampling and abductive reasoning to reach theoretical saturation. In this study, I did not treat theoretical saturation in conjunction with Charmaz's (2014) definition of theoretical sampling. The decision to stop collecting data was based on no properties of the categories found during the preliminary data analysis and when gathering data no longer sparked new insights. During the process of the full data analysis (after data collection), I re-examined the codes, subcategories, and categories in both Mandarin and English, and linked categories around the core category. The review of relevant theoretical literature was conducted during the full data analysis to compare and contrast existing theories and study findings (Corbin and Strauss, 2008). By the end of the data analysis, I did not find the need to collect more data. The reason could be that most of the interviews in this study lasted for two hours and the target groups in the sample were proportionally recruited considering the HIV epidemiology in Taiwan. In that regard, the rigour and efforts I invested in the data collection and analysis in the field sites seem to have enhanced the richness of the

data. Through the comparisons, differences identified were added to the current evidence base, resulting in creating new knowledge and building on the prior knowledge.

5.9. The quality of this qualitative study

Quality of qualitative research is produced and enhanced based on the transparency of the whole research process (Flick, 2007). Transparency is referred by Flick (2007) as "*making the research process, in its steps and in the decisions that influenced how data and results were produced, understandable to readers in the broadest sense* (p.137)." In that sense, the emphasis of transparency in qualitative research is placed on explicit documentation and being transparent to the readers what has been done, how it was done, and the result to which it led. However, in reviewing the criteria of qualitative research, it was revealed that its criteria vary within qualitative communities (Creswell and Poth, 2018, Charmaz, 2014, Chiovitti and Piran, 2003, Guba, 1981). Theoretical underpinnings or special purposes for a qualitative inquiry could generate different standards for evaluating the quality of qualitative research (Creswell and Poth, 2018). Congruently, Flick (2014) claimed that the issues relating to how to assess qualitative research remain unsolved.

To ensure the quality of this qualitative study, four criteria were taken into account− credibility, transferability, dependability and confirmability (Guba, 1981, Chiovitti and Piran, 2003).

5.9.1. Credibility

Credibility refers to "*the trustworthiness and plausibility of the research findings* (Tracy, 2010, p.842)". The credibility of qualitative research can be achieved through thick description, crystallisation and multivocality (Tracy, 2010). Thick description means that researchers should take into account data's complexity, and provide enough details that readers can understand the context and meanings (Tracy, 2010). During data collection, I treated participants with respect and dignity, which helped to ease tensions and gain

their trust. Having participants' trust seemed to increase their willingness to expand their experiences in depth and breadth, contributing to in-depth illustration that explicated culturally situated meanings and abundant details (Trancy, 2010).

Crystallisation means that if researchers collect two or more sources of data or use theoretical frameworks, the conclusion in the research is more credible (Tracy, 2010). In this study, I took observation notes during and after interviews to document participants' non-verbal languages, the interaction between me and participants, and the interview environment. These notes were used to compare with interview data, and socio-demographic information during data analysis, which helped to open up a more complex and in-depth understanding of participants' experiences.

Multivocality means that researchers can provide space for a variety of opinions. In this study, the use of theoretical sampling techniques allowed me to see the data from the perspectives of participants with different backgrounds, and thus the emerging conceptual model can be refined to all possible cases (Bitsch, 2005, Charmaz, 2014, Oktay, 2012). In addition, any uncertainties and questions regarding this project or participants were discussed with supervisors and attending physicians to seek different perspectives.

5.9.2. Transferability

Transferability is defined as "*the applicability of the findings to other settings* (Oktay, 2012, p.80)." To enhance the transferability of this research, constant comparison and adapted theoretical sampling approach were used to help to identify the variation in a category or process, and fill the gaps (Charmaz, 2014). The recruitment of HIV-positive drug users at different recruitment sites also helped to develop a conceptual model that can be generally applied to HIV-positive drug users in Taiwan.

5.9.3. Dependability

Dependability refers to "*the stability of findings over time* (Bitsch, 2005, p.86)." Due to the nature of grounded theory approaches, changes in concepts, interview questions and the focus of research are part of maturing and succeeding qualitative research processes (Charmaz, 2014). To ensure the stability of research findings, I kept track of the research process, my thoughts and questions raised during the study process, and any methodological decisions being made through memo-writing (Charmaz, 2014). These strategies were used to ensure the dependability of this study.

5.9.4. Confirmability

Confirmability is in parallel to objectivity, which is to deal with the issues related to bias and prejudices of researchers (Bitsch, 2005). This can be achieved by demonstrating transparency and sincerity (Tracy, 2010). To minimise the researcher's taken-for-granted assumptions and false information, reflexivity was employed throughout the project via memo-writing to trace the development of ideas and decisions with regards how concepts were defined, how and why participants were selected, how interview questions were developed, and how categories or concepts were generated (Chiovitti and Piran, 2003, Oktay, 2012).

Following the four criteria, I strived to demonstrate reasoned reflection and principled conviction. By doing so, it assisted this study in conceptualising and conveying what is meaningful in the field of illicit drug use, HIV and HAART taking, and making a valuable contribution to the field.

5.10. Summary

In this chapter, I have provided a detailed account of how this study was conducted. Issues and experience relating to recruiting and interviewing HIV-positive drug users, and the ways that I dealt with the issues were addressed. Recruiting HIV-positive drug users was challenging and required to gain access to their social networks. To do so, my relations with health professionals, social workers and potential participants needed to be constantly negotiated so that I could conduct adapted theoretical sampling. During interviews, establishing rapport with participants and gaining their trust were crucial. With their trust in me, they appeared to be more likely to open up themselves and share their stories. In turn, it assisted in achieving intimate familiarity with the research topic.

In terms of data analysis, it was evidenced that there is no standardised way of analysing data when translation to English occurs (Chen and Boore, 2010). Whether to analyse data in Mandarin or English was an important decision considering the meanings of participants' experiences were understood through their language. When involving translation, it added challenges to convey the meanings to readers with trustworthiness and transparency. In an attempt to minimise this risk, data in Mandarin were analysed first to capture the meanings in the original language. Then, the coded data in Mandarin were translated into English and re-coded and re-categorised in English to find the English terminology that is equivalent to the meaning of participant's experience. This analytic process was not linear, but rather it required me to trace back and forth between the data in Mandarin and English, the codes in Mandarin and English, socio-demographic information, and memos.

The preliminary data analysis in this study was done in Mandarin during my data collection, whereas the full and detailed data analysis was complete after data collection. Once deepening the analysis and developing categories (full data analysis), a review of theoretical literature was conducted to compare and contrast the existing literature with the findings of this study

(**Chapter 6-8**). This decision was made to minimise the risk of narrowing my thinking and blocking creativity (Strauss and Corbin, 1998). After the full data analysis and a review of theoretical literature, I did not find the need to recruit more participants.

Taken together, this chapter discusses the qualitative research methods used for this study and the process of data collection and analysis. The next three chapters that follow move on to focus on the research findings developed during data analysis— **Chapter 6**: HIV-positive identity as part of self-identity, **Chapter 7**: Value attached to HAART, and **Chapter 8**: Conscious actions. The integration of the three concepts along with how value emerged as the central category is discussed in the conclusion chapter (**Chapter 9**).

CHAPTER SIX: HIV-POSITIVE IDENTITY AS PART OF SELF-IDENTITY

6.1. Introduction

Data revealed that HIV was perceived as stigmatising and discrediting in the Taiwanese society. By living in the Taiwanese culture where HIV is highly stigmatised, participants appeared to internalise the social stigma and experience feelings of shame, denial, fear, uncertainty, desperation and hopelessness. These emotions participants experienced had affected the way they perceived themselves as HIV positive; handled the reality of being HIV positive and the consequences brought by it; managed HAART taking. During the process of identity re-construction following the new HIV diagnosis, participants' sense of self developed and changed over time. The greater degree to which they engaged with the social world the more resilient and self-accepting participants were more likely to be.

In this chapter, I begin by addressing the emotional impact of HIV diagnosis among HIV-positive drug users, followed by discussing how their HIV-positive identity as part of self-identity disrupted/facilitated their engagement with HAART taking.

6.2. HIV-positive identity as part of self-identity

HIV is a chronic and long-term health condition requiring participants to live with it for the rest of their lives. To live with it, affected individuals may need to reconcile their sense of self with the implications of HIV infection and impose coherence on an uncertain future. However, when losing sight of the centre in self and life, participants were adrift. As a result, it triggered their

feelings of uncertainty, fear, anxiety, shame and desperation, and threatened their ability to face themselves and the realities, to connect with others, and to cope with their HIV and its treatment.

The topic relating to new HIV diagnosis, and its emotional impact and impact on HAART taking are addressed under two main sub-categories— emotional impact of HIV-positive diagnosis, and new identity construction in response to HIV diagnosis within the Taiwanese context. An overview of the concept— HIV-positive identity as part of self-identity— is presented in **Table 7** with categories and sub-categories.

Table 7: Constructs of HIV-positive identity as part of self-identity

<table>
<tr><th>Concept</th><th colspan="2">Category</th><th>Sub-category</th></tr>
<tr><td rowspan="8">6.2. HIV-positive identity as part of self-identity</td><td rowspan="4" colspan="2">6.2.1. The emotional impact of HIV-positive diagnosis</td><td>6.2.1.1. Feeling of uncertainty</td></tr>
<tr><td>6.2.1.2. Avoidance of difficult emotions
- Self-denial of HIV status (6.2.1.2.1.)
- Lifestyle behaviours as coping strategies (6.2.1.2.2.)</td></tr>
<tr><td>6.2.1.3. Desperation</td></tr>
<tr><td>6.2.1.4. Suicidality</td></tr>
<tr><td rowspan="4">6.2.2. Identity re-construction in response to HIV diagnosis</td><td rowspan="2">6.2.2.1. Non-integrated self-identity</td><td>6.2.2.1.1. Shame and self-stigma</td></tr>
<tr><td>6.2.2.1.2. Non-disclosure of HIV status</td></tr>
<tr><td rowspan="3">6.2.2.2. Integrated self-identity</td><td>6.2.2.2.1. Accepting HIV status</td></tr>
<tr><td>6.2.2.2.2. Selective disclosure of HIV status</td></tr>
<tr><td>6.2.2.2.3. Feeling supported</td></tr>
</table>

Figure 8 presents HIV-positive drug-taking participants' self-identity re-construction conceptually as a framework to build on and to ultimately develop a model for sustaining HIV-positive drug users' HAART-taking behaviour (**Figure 9 and 11**).

Figure 8: Self-identity reconstruction

6.2.1 The emotional impact of HIV-positive diagnosis

This section firstly discusses the emotional impact of receiving an HIV-positive diagnosis on participants and how such emotional impact had affected their HAART taking.

6.2.1.1. Feeling of uncertainty

In this study, upon diagnosis of HIV, participants, on the whole, demonstrated a general sense of uncertainty, and by association fear and anxiety. Their fear and anxiety appeared to be derived from the perceived stigma attached to HIV, and not knowing what to do and how other people would view them or react towards their HIV status.

> "*If I want to be in a relationship with a person, I need to respect him. I am afraid that the person would keep distance with me. I don't want people to view me differently.*" (P4, MSM, 26y)

> "*I just feel HIV doesn't sound good. I am afraid that other people will view me differently. Psychologically, I cannot get over it. Being with people with HIV in jail, I didn't need to hide my status. Since I was out of jail, people don't know my HIV status, I need to hide it. I am so afraid I*

will accidentally reveal my HIV status to other people and how they will react." (P18, Female heterosexual, 32y)

HIV is stigmatising in the Taiwanese society, and thus living with HIV has brought fear and anxiety to some participants. In the cases of P4 and P18, their sense of uncertainty appeared to be internal as they were unsure and feared the negative consequences of living with HIV and how it would affect their relationships with others. Such feelings were revealed within data to create barriers to seeking out support. The finding is congruent with Bury's (1982) biographical disruption. In this theory, Bury (1982) contended that the emergence of a chronic illness can shift an individual's perception of life from a normal and relatively predictable to an abnormal and inwardly damaging. When viewing the condition as an outside force, affected individuals could feel its invasion into all aspects of their life, leading to the feeling of fear, anxiety, and uncertainty, especially about their future (Bury, 1982). 'Uncertainty' has been defined by Mishel (1988) as "*the inability to determine the meaning of illness-related events* (p.225)." 'Diagnosis' is principally epiphanic as a moment of change (Karnilowicz, 2011), which can be regarded as positive or negative experience (King et al., 2003). Such experience can alter an individual's fundamental meaning structures and change the concept of self (King et al., 2003).

By the same token, P5, P10 and P12's statements shown below alluded to the notion that they were not able to envision their future as positive with their past and present realities. The development of negative emotions is due in part to the mismatch or increasing discrepancy between meanings perceived in the situation and meanings held in the desirable prospects, causing status inconsistency and role conflict (Stryker and Macke, 1978). P5's accounts below illustrated his past experience of public stigma, and fear of family' rejection. His past experiences of stigmatisation and seeing others with HIV influenced how he perceived himself as HIV-positive. As a result, such experiences intensified his feeling of uncertainty about the future and influenced whether he wanted to disclose HIV to gain support. Similarly,

P12's narrative also showed his sense of uncertainty upon the diagnosis of HIV. The epiphanic illness experience triggered his emotional response and created the conflicts between his sense of self and perception of the new HIV-positive identity.

> "*I am so afraid that my family will discover my HIV. I feel ashamed to tell them. I cannot face it. If I can deal with it on my own, I will just do it on my own…I am still against this reality. Before, when I went on trial, the clerk of court handed over a document to me, like this* [Fieldnote: P5 demonstrated the clerk's gesture. Her gesture was like she didn't want to touch him. She kept her hand as far away from his hand as possible. After handing over a paper to him, she cleaned her hand with her cloth]*. I thought whether I was still a human being.*" [Later in the interview, he stated] "*I have seen HIV- positive people who were severely ill. I helped those people in the charity. And I started to think about my future. If I am like them, being abandoned by family and not being supported by anyone, I will feel sad*. *I am worried about my future.*" (P5, Male heterosexual, 45y)

> "*After my HIV status was confirmed, I was thinking what I should do next. My mind went blank for two days. I didn't know what to do. My mind was absent. At the time, I just finished my master programme. Then I was hesitating if I should go to the hospital and receive treatment. This emotion lasted for one to two weeks*" (P12, MSM, 35y)

On the other hand, the extract presented below from P10, "*Afterwards because my ex-mother-in-law accepted me, I started to accept myself*", shows that with the support from others, it seemed to provide a sense of continuity in her life, thereby reducing the amount of perceived uncertainty. Congruently, Bury (1982), Gergen (2001) and Riley and Burke (1995) supported the importance of maintaining good relationships with others during the illness trajectory. The extent to which a person can verify his/her self-identity depends on the identities of others, how others respond to identity claims, and whether an individual's behaviour can alter the situation

to align perceived self-meanings with identity standards (the identity goals that an individual wants to achieve in a situation) (Riley and Burke, 1995). By bridging the gap between perceived self-meanings and identity standards, it can enhance an individual's psychological well-being, motivational force, and satisfaction with the identity (Riley and Burke, 1995).

> "*While I was pregnant, I just knew that I have HIV. I felt like I was in miserable having HIV. I was also afraid and concerned about whether my baby would be infected. Sometimes, I really wanted to take this unborn baby with me and committed suicide. Afterwards, because my ex-mother-in-law accepted me, I started to accept myself.* [Earlier in the interview, she stated] "*I started to use illicit drugs at the age of 17, and then I used heroin and smoked at the age of 18. Then I injected heroin at 19. Before 2003 I wasn't infected with HIV, because it is mandatory to have HIV screening. Then I was released. I found I was infected after I was caught by police again and being put in jail in 2005. I was at the 8th month of pregnancy at that time. The staff at jail referred me to a doctor and had screening tests for my pregnancy. HIV screening was positive. Thus, I started the treatment at the 8th month of pregnancy"* (P10, Female heterosexual 33y)

The data presented so far provide an important insight that in face of new HIV diagnosis, some participants felt anxious and uncertain about how to live with HIV and how it would impact on them. Their feelings of anxiety and fear were often combined with other negative emotions depending on personal circumstances. When the emotions were too overpowering, it affected how participants handled the situations and dealt with their emotions, which is discussed in the next section.

6.2.1.2. Avoidance of difficult emotions

Participants' emotion is a multi-layered process in which their feeling of uncertainty about life with HIV often tightly coupled with other emotions. There were a number of participants who tended to avoid handling the situation and facing their difficult emotions by being in denial and engaging in

illicit drug use. Their denial of HIV status and the impact of drug use on their lives appeared to pose a negative impact on their HAART-taking behaviour. This section firstly focuses on participants' self-denial of HIV status, followed by their lifestyle behaviours, and how avoidance of difficult emotions affected their engagement with HAART-taking.

6.2.1.2.1. Self-denial of HIV status

At an early stage of HIV, it seems that HIV could impact on an individual's original sense of self and result in an imbalance between an original sense of self and this new HIV identity, leading to a denial of HIV status. In this study, many participants unwillingly faced the reality of being HIV positive and accepted it upon the diagnosis. Data revealed that most participants had developed negative emotions towards their HIV diagnosis. The negative emotions were particularly intense at the beginning of the HIV trajectory.

> *"When I was diagnosed with HIV at the first one or two months, I was really emotionally unstable*. *HIV didn't sound good. It made me feel guilty and defined myself negatively.*" (P12, MSM, 35y)

> "*At the beginning, it was painful to accept it. It was shameful. I was in denial. I might have viewed HIV as a horrible disease. It was like you still held the earlier value of what HIV was*." (P14, MSM, 36y)

The excerpt from P14, '*it was like you still held the earlier value of what HIV was*', indicated that his perception of HIV was influenced by the social image of HIV portrayed by the Taiwanese society. The social value was deeply ingrained in his mind. By holding the negative perceptions of HIV, his possession of the new HIV status appeared to trigger his negative emotions towards it. The transcript extracts from P12 and P14 — '*HIV didn't sound good*', '*it made me feel guilty*', '*it was shameful*', '*viewed HIV as a horrible disease,* and *'defined myself negatively*' — illustrated that participants' negative emotions towards HIV exerted an impact on the way they evaluated themselves as HIV positive. When not being emotionally prepared to live with it, some participants were in denial of their HIV status.

"*I think it is important to accept self. They don't accept themselves, and keep avoiding the HIV specialist. They are still in that drug circle. I kind of understand them. In the past, the nurse called me back. I kept avoiding her. I can understand that kind of feeling. I just didn't want to face it.* " (P4, MSM, 26y)

"*HIV is negative…I couldn't accept it. Felt why me why me…I felt hatred, why that person didn't inform me and then transmited the virus to me.*" (P2, MSM, 32y)

In Matsumoto and Juang's book (2008), *Culture and Psychology*, they pointed out that culture can influence an individual's way of perceiving things and interpreting information. The extract from P2, "*why me. why me*" and "*that person didn't inform me*", reveals his anger and the unexpectedness of getting HIV infection. The negative emotion and unexpectedness seemed to affect how he viewed HIV and his readiness to face such reality. It has been proposed that the unplanned or uncontrollable acquisition of the illness can obstruct the re-shaping of self-identity, which is especially fundamental when making a transition to incorporate chronic illnesses into life (Hyden, 1997, Karnilowicz, 2011, Telford et al., 2006). This notion resonates with P2's statements of "*HIV is negative*" and "*I cannot accept it*", showing his negative perception of HIV and unacceptance of the epiphanic experience of being HIV positive. As a result, an illness could lead to moments of psychological vulnerability and loss of personal power and control (Gergen, 2001, Pierce et al., 2003). Vulnerability can be real or imaginary, negatively affecting an individual's feeling of self-worth and self-confidence (Gergen, 2001). Consequently, affected individuals may present a feeling of denial (Telford et al., 2006).

Apart from P2 and P4, it was evident within the data that by not accepting the persons they were as HIV positive, P12 and P14 tended to care less about HAART and to lack readiness of taking HAART regimens.

"*I thought why I needed to accept it. It was humiliating. I kept telling myself I didn't have it. I denied that I have been infected with HIV, and thus I didn't receive treatment. I had that transition period of denying my HIV status*." (P14, MSM, 36y)

"*At the very beginning, I was in denial and refused to take the medications. I was internally struggling and having many negative emotions."* (P12, MSM, 35y)

By and large, participants' internal struggles and denial of HIV infection influenced their readiness to receive HAART and/or ability to manage regular HAART use.

6.2.1.2.2. Lifestyle behaviours as coping strategies

Upon learning the new HIV status, some participants developed negative emotions and were unready to face this reality. This is exemplified by P8's and P13's narratives presented below. The findings show that their negative emotions and unwillingness to deal with stress led them to start or continue using drugs in an attempt to avoid dealing with the unpleasant things that happened to them.

"*Drugs can make you want to avoid and be lazy. You wouldn't want to face anything outside. I sometimes used drugs to avoid and not face reality. When you encountered something and didn't know how to handle, you would inject it* [heroin]. *Once it is injected, you would feel drowsy and sleepy and not do anything, becoming a lazy person. To avoid reality, I would use it.*" (P8, Male heterosexual, 49y)

"*My grandnanny had a stroke, and was bedridden, and plus I am infected with HIV. I felt really distressed. Using Ketamine made me indulge in its effects and feel relaxed. It made me keep using it, avoiding things.*" (P13, MSM, 31y)

Participants' accounts illustrated that there were some challenges they have encountered in life. When confronting difficult truths, such as HIV illness and

family crises, some drug-using participants tended to avoid facing their negative emotions and the hard truths. The findings are closely linked to a paper by Anderson (2003) in which he described when the situations do not meet a person's choice, the person is more likely to avoid or to seek an easy way out that involves no change, in hopes of mitigating negative emotions. Congruently, it was evident from the data that drugs were a source of obtaining happiness and avoiding stress. Such rewarding effects led them to repeatedly use drugs, forming a circular process of feeling down, using drugs, and feeling happy.

> "*In the past, my gangster life was all about stealing, robbery, and killing. During that period of time, I would use heroin whenever I wasn't in a good mood. Once I repeatedly used drugs, I was addicted to it and couldn't live without it*." [Later in the interview, he said] "*After I got HIV, I couldn't face it. I couldn't bear it. I felt ashamed. I didn't have the courage to seek HIV care. During that time, I had many convictions. I was under arrest and Centre for Disease Control was also looking for me."* (P5, Male heterosexual, 45y),
>
> "*Walking on this path [HIV] is tough and lonely."*[Asked about his family's support, he stated that] "*Although on the surface they didn't give up on me, psychologically I still feel they hold the grudges…My life has been changed, being HIV positive, losing my job, breaking up with my partner, and my family."* [Later in the interview, he talked about his experience of his amphetamine use] "*It smelled good, like lavender having healing effects. It was healing. Then gradually I am used to it…When using it, it was pleasurable. Afterwards, I felt empty again. It wasn't okay afterwards, because it wasn't real. I think now I am controlled by drugs…When I used drugs, my use of medications might be irregular. I don't know. I don't remember. I want to quit drugs. Seriously. Now I don't have a partner. I need a partner so that we can support each other to go through the process*" (P2, MSM, 32y)

Sinha (2001) examined empirical evidence on whether the exposure to stress could increase drug use. He concluded that stress may increase one's vulnerability to drug abuse and alter stress response and coping, whereas he claimed that the mechanism underlying the associations is unclear. In this study, P2's and P5's narratives presented above— "*I would use it whenever I wasn't in a good mood*", "*having healing effects*", "*it was pleasurable*", "*Afterwards I felt empty again"* illustrated that in response to difficult emotions they used drugs to pursue happiness and fill a void of emptiness.

Data presented below show that P7 and P12's use of drugs as coping strategies and psychological dependence undermined their ability to control their drug use. As a result, their lack of self-control over drug use influenced medication taking.

> "*I started to use a large amount of amphetamine after I broke up with my boyfriend. I kept thinking and working crazily. I felt unhappy and down. During that time my family just discovered my situation [HIV], but I wasn't willing to listen to any positive encouragement. I only listened to my negative thoughts. I became very negative. I wasn't good enough. Thought that no one liked me. Since October, you can see that I have stopped taking medications for a month. I didn't go refill the medications*. *In the end of October, I just realised that I haven't taken medications for a month.*" (P12, MSM, 35y)

> "*When using amphetamine, I would find that. I mean when using too much of it, I would dwell on my unhappiness and not take medications. Then my viral load would go up*." (P7, MSM, 30y)

In line with the findings, it has been documented in Baler and Volkow's (2006) paper that the reinforcement of drug effects can negatively impact users' ability to cognitively control themselves and to make a rational decision (Baler and Volkow, 2006, De Wit, 2008). Moreover, the transcript extract presented below pointed to the notion that participants' psychological

dependence and experiences of withdrawal symptoms resulted in being trapped in a vicious cycle of using drugs and finding drugs.

> "*Heroin's withdrawal symptoms would make you crazily tried to find heroin until you found it. No matter how much time you spent on finding it you would do it until you found it. It was impossible to let myself in pain too long. I wouldn't think of the treatment. Wouldn't think that far. We would just want to solve current issues. That wasn't an immediate need*." (P18, Female heterosexual, 32y)

> "*I would rather spend money for drugs. After injecting drugs, I only thought of my next dose of drugs and how I could get money. To have a regular life was difficult. Generally speaking, people would normally care about their birthday. When using drugs, we wouldn't celebrate a birthday and even couldn't remember it. Even on Chinese New Year, all I thought about was drugs and next doses of drugs*." (P20, Female heterosexual, 36y)

According to De Wit (2009), drug users' negative mood states were linked to self-regulation of behaviour where emotion may impair their ability to focus on long-term goals by increasing their bias towards immediate pleasure. This notion is congruent with P18's and P20's statements— "*I wouldn't think of the treatment. Wouldn't think that far* " and "I *only thought of my next dose of drugs."* Consequently, their psychological and physical dependence on drugs appeared to collectively increase the difficulty of caring about their health.

By shifting focus onto finding and using drugs, participants' comments illustrated that establishing a regular lifestyle became challenging because of the amount of time, and physical and conscious efforts they spent on using/finding drugs and chemsex.

> "*When I used drugs, to take the treatment was almost impossible. I couldn't have time to handle the withdrawals, how come I would think of seeking medical attention. Hence, seeing a doctor became irregular,*

because it is required to visit a doctor every three months." (P15, Male heterosexual, 53y)

"*I used Ketamine and then fell asleep. I would wake up whenever I wanted to. I never cared about the time. When I woke up, it didn't matter what time it was. I did whatever I wanted and then fell asleep again. During the sleeping times, I am not sure if I have missed doses. Using drugs made me lose appetite. I was quite skinny at that time. I lost 5-10 kg. I didn't regularly have meals, and I didn't want to eat. How come I would want to take medications?*" (P13, MSM, 31y)

"*When using drugs*, *my lifestyle wouldn't be regular. I wouldn't sleep at night. Didn't sleep much. I didn't even eat meals regularly. So my intake of medications would be erratic.*" (P4, MSM, 26y)

In living a life with HIV and illicit drug use, another concern brought up by participants was the illegality of drugs. Their lifestyle appeared to be chaotic not only due to the influence of drug taking but fear of being caught by the police. Collectively, participants' fear of facing negative emotions and difficult realities, such as dealing with HIV, drug dependence, and law enforcement, appeared to leave them no choice but live in the shadows. Subsequently, the adversities participants encountered in their life with HIV and drug use had created a multi-layered barrier to receiving or regularly taking HAART. The findings are in line with De Wit's (2009) study that disruptive environment was associated with inappropriate or maladaptive behaviours among drug users.

"*I have many friends who had that experience. They went see a doctor but were caught by police. Or the police would wait outside the hospital. Don't you think it would be affected? Police officers were really good at tracking. If he still uses drugs, you can see if he will still come to the hospital. They must not have the gut to come. They'd rather not take antiretroviral treatment*. *If I am still using drugs, it is impossible for me to come refill the medications*." (P8, Male heterosexual, 49y)

"*The main problem is drugs. They cannot quit drugs. How come they want to see a doctor? They just cannot quit drugs. How can they manage to see a doctor? Some have been caught by police. They would be afraid it was a trap. Others would think why you wanted to treat me well. Will you sabotage me? I have tried to encourage 5-6 people to come see a doctor. But failed every time. I couldn't persuade them. Some have seen a doctor but escaped. It is very complex. There are many things that are linked to influence our medication taking.*" (P4, MSM, 26y)

In summary, though drugs were acknowledged by many to bring negative consequences, such as withdrawal symptoms and psychiatric symptoms, most described their experiences of using illicit drugs was positive and hard to be replaced. Participants' use of drugs and its impact on HAART taking was particularly found to be prominent in the situation where they had difficulty handling their negative emotion. In turn, drug use appeared to provide a comforting and soothing space where they could lie in an attempt to avoid stress, find happiness, and meet immediate physical needs of avoiding withdrawal symptoms.

6.2.1.3. Desperation

Karnilowicz (2010) in his paper discussed that the effects of an illness can be debilitating and confronting, and over the course of the illness, it requires an individual to gain control over its effects by having some levels of psychological ownership. However, in this study, upon receiving an HIV diagnosis, many participants felt distressed and despair.

"*After the diagnosis of HIV, I rarely got in touch with other people. I locked myself in my room. At that time, I felt depressed*." (P4, MSM, 26y)

"*HIV is negative and the medications make me think of HIV. Thinking of disgusting things. It is like I deserve it because I am promiscuous*." (P2, MSM, 32y)

> "*When I was diagnosed with HIV at the first one or two months, I was really emotionally unstable*." (P12, MSM, 35y)

Data presented above revealed that the state of desperation could warp participants' thinking, allowing them to dwell on negative thoughts, such as "*I deserve it because I am promiscuous*" (P2, MSM, 32y) and "*why should I take those pills and why should I live long*" (P11, MSM, 31y). With the feeling of desperation, some perceived themselves negatively and viewed their future with uncertainty. By repressing their emotions to support negative thoughts, they seemed to have fallen prey to such thoughts.

> "*When alone, I would be more negative, thinking this illness is not curable. Thought that why I should take those pills and why I should live long*."(P11, MSM, 31y)

> "*I knew that HIV won't make me die, and the treatment can prolong my life. However, my first reaction was like I am done. This is the first reaction. Second, I couldn't handle a family crisis. My grandmother had a stroke and lied on the bed but nothing I could do about it. I wanted to die.* " (P13, MSM, 31y)

In the case of P13, he was emotionally affected not only by HIV status but his family crisis. His exposure to multiple adversities had increased his stress level and led to feelings of desperation and inability to cope with the emotions. This indicates the close and ongoing interaction between individual psychological state and social environment (Pierce et al., 2003).

In turn, it was evident within the data that participants' negative thinking along with feelings of desperation could sow the seeds for eventual hopelessness.

> *"I don't blame others for why I got HIV but myself. When I just got it, I felt hopeless. In the past, we called it as a black disease. It's not like now that it is a chronic disease."* (P22, Male heterosexual, 50y)

“I was about to commit suicide. I felt hopeless. I was down. I was under arrest. I had committed many crimes. Also, I was sick. I completely sank into despair.” (P20, Female heterosexual, 36y)

Participants’ accounts alluded to the notion that when in desperation some felt that they failed in some way or they were the cause of their own issues. Eventually, such intense feelings of desperation and hopelessness led them to feel stuck in life with no way out.

6.2.1.4. Suicidality

During the process of HIV and HAART trajectory, some participants had encountered difficulties in life, such as HIV-related health issues, financial difficulties, or family rejection. According to participants’ statements, these circumstances appeared to overwhelm them.

“*I wasn’t in a good mood. I thought why I was in such a bad luck, having HIV and nasopharyngeal cancer.*” (P22, Male heterosexual, 50y)

“*I felt down. I didn’t want to live anymore. I was just recently back from jail. I wasn’t well. My spine wasn’t well, and I couldn’t work. My financial status wasn’t good.*” (P17, Male heterosexual, 37y)

Data revealed that experiencing one setback after another increased participants’ sense of worthlessness in life, and caused to question whether their lives have any meaning or hope.

“*I went to have HIV screening at the second time. It was positive. I don’t remember which doctor. Anyway, I felt nothing was more important than drugs. At that time, my dad, mum, sister and brother were really disappointed in me and I let them down*. *They asked me if I wanted to quit drugs, and I said yes. But later I was craving for heroin. They said if I used it again they would kick me out of the house. Then I told my mum I wanted drugs. I didn’t want mum and dad. Then I ran away. I lived in a park or houses that were under construction. After a while, because of my HIV, my mum was worried about me, and came find me in a park*

and let me live in my sister's apartment on my own. They sometimes secretly put food and snacks in the apartment. But at that time I didn't have money to buy drugs. I was left to fend for myself. I remember one day I walked on the riverside, and I thought why my life became like this. I thought of suicide" (P19, Male heterosexual, 43y)

"*Why all the bad things happened to me. I didn't want to receive treatment. Just let it go*. *Taking chemotherapy medications was suffering. I thought of not taking any of my medications* [Including HAART]." (P22, Male heterosexual, 50y)

The participants' accounts also pointed to the notion that their feelings of worthlessness led them to not see any aspects of life as positive and not believe there was the prospect of improvement.

"*I've never thought of my future. If I die by not taking the treatment, then just let it be. Just passively waiting for death's coming*." (P18, Female heterosexual, 32y)

"*I started to give up myself, looked for negative things and imposed those on myself. Thought negatively and let myself go and did whatever I wanted*." (P7, MSM, 30y)

When not seeing worth in their life some participants did not lead their life proactively, and this could translate into engaging in self-destructive behaviours.

"*Since I got it* [HIV]*, I have felt hopeless. I had a wonderful family, my ex-wife and kids. Since I got it, my wife and kids were gone. I started to live my life in a destructive way."* (P17, Male heterosexual, 37y)

"*I wanted to die, but I was afraid of pain. I thought if I used a large amount of ketamine to let myself die without experiencing pain. But I didn't die. I really gave up myself that time."* (P13, MSM, 31y)

There was a small number of participants having support from family and/or friends but feeling unmotivated to move forward in life. In the example of P18, during her pregnancy, she received HAART. After delivery, she had treatment interruption. The reasons behind her decision of not receiving the treatment were later revealed to be due to her perceived stigma related to HIV (**Section 6.2.2.1.1**.), feeling of hopelessness, and perceived burdensomeness (e.g. "*I feel this disease is awful and not curable*", "*Yes, I don't want to give them* [family] *burden.*", "*I feel I am different from them*."). Based on her narratives below, her dwelling on negative emotion towards living with HIV seemed to strike her. In turn, the disruptions caused by HIV-positive identity influenced how she coped with HIV and its treatment (**Section 6.2.2.1**).

> "*I was caught by the police. Then they took me to have screening tests. The result was positive. In the morning, I found I was pregnant, and in the afternoon I found I was HIV positive. Then I received cocktail treatment in jail during my pregnancy. My child is negative.*" [When I asked the reason she stopped taking the treatment after baby delivery. She said] "*I don't know. Just don't want to take it"* [Later the interview we discussed her family, and she told me] "*My mum, from the very beginning, took care of me, and took me wherever I wanted to go. My dad didn't say much, but once he told me privately that whatever I wanted he would buy it for me*. *My partner also cares about me. But I still feel we are living in the different world…I can't get over it* [HIV]…*I want to die. A long time ago I have already thought that. I feel this disease is awful and not curable…If I die by not taking the treatment, then just let it be. Just passively waiting for death's coming*." [I further asked if she did not want to give her family burdens] "(nodding) *Yes, I don't want to give them a burden. And I feel I am different from them*."(P18, Female heterosexual, 32y)

> "*Keeping encouraging may not work. Outsiders' encouragement is needed, but the key point of keeping moving forward in life is dependent*

on an individual himself/herself. Some did not have life aspirations and gave up taking the medications, even though their family accompanied them and refilled the medications for them." (P20, Female heterosexual, 36y)

The findings presented so far are supported by the interpersonal theory of suicide by Van Orden et al. (2010). They proposed that thwarted belongingness (beliefs that individuals' needs are unmet) and perceived burdensomeness (the extent to which individuals perceive to be a burden on others) are dynamic interpersonal states that could engender suicidal thoughts and attempts.

Based on participants' statements, though participants had support at hand, when not taking the support into their heart they could still be emotionally oriented by what concerned them the most. In other words, it seems that when individuals are not accepting and supporting themselves, and feeling worthless, no amount of argument could compel them to see the world differently. As a result, those who felt life was not worth living tended to be passive, and less engaged in medical care and general socialisation. Similarly, in the current evidence base, empirical studies have shown that depression and suicide were common among the HIV positive population, and related to lack of social support and HIV-related stigma (Carrico et al., 2007, Heckman et al., 2004, Sherr et al., 2008).

"*I am HIV positive. Then I also get cancer. I oftentimes thought of suicide. I didn't receive any treatment. Just let myself go. At that time, I didn't come to infectious diseases outpatient services for several months*." [During the interview, he also stated his suicidal attempts] "*I was very negative. I often thought of suicide. I even burned charcoal to kill myself, but it wasn't successful, and I didn't die."* (P22, Male heterosexual, 50y)

> "*I don't want to receive the treatment*. *I want to give up. I don't like to go out. Previously, people couldn't find me. I was hard to find*." (P18, Female heterosexual, 32y)

In short, based on the data, it implies that as outside circumstances become less and less bearable, it increased participants' tendency of perceiving as if they had no significance or purpose of living in this world. Consequently, their inner sense of worth diminished, leading to suicidal attempt and behaviour. Such negative perception might result from their mal-adaptation of negative emotions towards stress.

6.2.2. Identity re-construction in response to HIV diagnosis in the Taiwanese society

At the time of HIV diagnosis, participants needed to face this reality and learn how to live with it. Their emotional response to their HIV and perception of the meaning attached to this influenced their sense of self. In the dynamic process of identity re-construction over the course of HIV trajectory, whether or not participants integrated HIV into self-identity emerged within analysis to influence their ability to manage their HIV and HAART.

6.2.2.1. Non-integrated self-identity

In this study, HIV infection was portrayed negatively in the Taiwanese society. When not viewing HIV as part of self, participants were inclined to feel ashamed and not disclose their HIV status; thereby it could be proposed that this undermined their internal strength to manage HIV and its treatment. This section first discusses how participants' sense of shame and self-stigma were constructed, and then moves on to discuss the impact of self-stigma on participants' decision to not disclose HIV status and seek support, and then looks at how these elements of non-integrated identity collectively influenced participants' HAART-taking.

6.2.2.1.1. Shame and self-stigma

In a systematic review by Katz et al. (2013), HIV-related stigma was found to compromise participants' ability to adhere to HAART. In this study, data

revealed that HIV was portrayed by the Taiwanese society as being equivalent to other attributes, such as promiscuity, homosexuality, and illicit drug use. Public perceptions of HIV surfaced mainly in respect to the ways affected individuals were infected. It is exemplified by participants' experiences presented below regarding their perception of how the public perceived HIV:

> "*Getting HIV meant that my life was ruined, because when I was little ads said that HIV infection was caused by promiscuity. The ads educated us to not have sex with many people and to remember wearing condoms; otherwise, you would get HIV. This was the aim of the ads. That's why I felt HIV was a shameful disease."* (P10, Female heterosexual, 33y)

> "*The public thinks that HIV means gay men. I also think so. There is a reason behind it. You can see that why HIV prevalence among heterosexuals is so low. There must be a reason behind it. This is not the public view solely on homosexuality but on sexual behaviours related to HIV in gay men. In this society, sexualism is no longer an issue. The main problem is gay men themselves. If we don't change our perception and behaviour the rate of HIV infection will continue increasing. This is not public prejudice."* (P1, MSM, 28y)

> "*HIV. HIV. You told people you are HIV. They may think how you got it. It is awful even just hearing this word."* (P15, Male heterosexual, 53y)

> "*In the past, my son warned that many drug users got HIV and wanted me to not use drugs.*" (P5, Male heterosexual, 45y)

These accounts point to the notion that the negative image of HIV is not only created by HIV itself but the socially-unacceptable behaviours attached to it. As a way in which to explain participants' behaviours, they were classified into different social groups in society. Congruent with the findings, Goffman (1963) termed 'stigma' as a 'moral career' where it occurs as a new social identity through social interactions. As P6 said below, drug users and MSM

are regarded as marginalized populations in society and are closely related to HIV infection.

> "*People with HIV and drug users are quite similar. They are regarded as marginalised populations. They are related, in terms of their social status and their experiences of unfair treatment from society. Even you don't have HIV, they may think you have. In the same logic, being gay, people may think you have HIV*." (P6, MSM, 52y)

Stigma is embedded in one's interpretation of social context, which involves cultural meanings, psychological states, roles and ideal types (Yang et al., 2007). The multi-layered and negative social images of HIV were revealed within the data to influence the way participants evaluated themselves as HIV positive. For example, participants' statements "*I felt HIV was a shameful disease"* (P10, female heterosexual, 33y), "*It is awful even just hear this word*" (P15, Male heterosexual, 53y), and "*It is a shameful disease*" (P16, male heterosexual, 42y) presented their feelings of shame by carrying the stigmatizing HIV-positive identity. When participants' emotions towards "stigmatising HIV" were overpowering, the amount of knowledge they have learned relating to HIV was completely subsumed. This is exemplified by P2 and P19.

> "*HIV is a chronic illness. If not controlling it well, it can develop AIDS. If it is controlled well by medications, we can live longer. It is just a statement. You feel like you still live with it day by day*." (P2, MSM, 32y)

> "*It is social value. While current medical technology is advancing, HIV is just a chronic disease, however, when it comes to social value, I think how to solve the issue of HIV stigma becomes difficult and unanswerable.*" (P19, Male heterosexual, 43y)

In addition to self-perception of HIV, personal experience of discrimination and stigmatization appeared to increase their sense of shame and self-stigma.

"*One time, I asked my mother to come with me to visit the HIV specialist. After this visit, she eventually chose to not get over it* [HIV]*. Because at the beginning her first reaction was like if it could affect her. That was her reaction! Then the HIV specialist said from the bright side she at least didn't give up on you. I felt that she didn't give up on me on the surface, but maybe psychologically she still… Because previously she had warned me to not be gay.*" (P2, MSM, 32y)

"*After I told my family about my HIV status, they kicked me out of the house. Then I rented a shared flat outside. During that period of time, I often forgot my medications because I was living sinfully and kept dwelling on negative thoughts.*" (P7, MSM, 30y)

Stigma is viewed as a moral issue by anthropologists, in which stigmatised condition could threaten what matters for affected individuals and intensify the sense that life is not certain and is dangerous (Yang et al., 2007). In the case of HIV, the cultural images of HIV connect the social values into an affected individual's inner world of feelings (e.g. shame) and physical experience (e.g. loss of social position and ostracisation) (Yang et al., 2007). In that regard, stigma is emergent not only as responses of psychological defence but in the moral and existential experience that an individual is threatened.

Participants who perceived themselves negatively were inclined to lose their sense of self with HIV (inwardly), which further impacted their engagement with HAART taking (outwardly). Commenting on this, some participants stated that HAART reminded them of their HIV status. By linking HAART with HIV, their lack of self-acceptance of HIV status exerted a negative influence on participants' engagement with HAART taking.

"*I felt ashamed of myself and avoided the crowd, starting to lose the sense of myself…Cocktail treatment is equated with HIV. It is the same thing. Most people wouldn't reveal what they are taking. I rarely saw people who used antiretroviral treatment. Even though they used it, they*

wouldn't reveal they were taking the treatment. They wanted to save face. It's common in the Taiwanese society."(P7, MSM, 30y)

"*They [medications] reminded me that I had problems in my body. This would affect my regular use of medications. I think that you may have heard other people viewed the treatment negatively and had many negative emotions. It just reminded me that I have HIV*." (P12, MSM, 35y)

In participants' accounts presented above, they avoided or irregularly took HAART regimens in an attempt to 'save face' and keep painful or undesirable emotions towards HIV out of mind. P7's mention of saving face means preserving one's dignity. Being HIV-positive was perceived shamefully by many participants. Their perceived stigma related to living with HIV had decreased their willingness to take HAART medications openly so as to avoid stigmatisation and preserve their dignity in the Taiwanese society. This evidence resonates with the notion proposed by Scambler (2008) where "the discreditable" attempted to "pass as normal" to avoid stigmatisation.

In addition, the visible or publicly known signs can also lead to the risk of stigmatisation, which is called "the discredited" by Scambler (2008). It was evident in the data below that the appearance of HAART medications and side effect of HAART on user's body image were perceived as symbolic of HIV. In such conditions, Goffman (1963) called it as physical stigma where physical signs of stigmatised conditions are present and visible to others. When taking HAART regimens in public, some were concerned about the possibility of their HIV identity being discovered. Their perceived stigma related to HIV and non-integration of HIV identity into part of self-identity was revealed within the data to undermine their willingness to regularly take medications or refill medications.

"*When I was working in [xxx], I was afraid that people would see my pills. Thus, I didn't take the medications most of the time. I felt uncomfortable letting other people know my privacy. I felt ashamed.*

Many people rather decided to not take the treatment." (P5, Male heterosexual, 45y)

"*The medications looked distinct. I cannot do it. If taking them in public, it is hard to explain*." (P13, MSM, 31y)

"*I cannot take them outside. I just cannot do that. Really.These are not like other medications. They look really different from medications for other chronic diseases. Also, if we can refill the medications in pharmacies, I don't think I have the courage to refill them there other than hospitals. I just feel weird. I will try to avoid* [implicit meaning in Mandarin: avoid the possibility of being discovered.]" (P15, Male heterosexual, 53y)

Participants' statements presented below illustrated that by experiencing a change in appearance and losing weight due to side effects of HAART, it had made their HIV identity more visible, intensified their perceived stigma and vulnerability, hindered social interactions, contributing to intentionally skipping doses. Their experiences of side effects were reported to be more likely to occur at the beginning of taking a new regimen.

"*At the first or second month of taking the medications, I really wanted to stop taking the medications. I was experiencing some symptoms, inability to concentrate, dizziness, diarrhoea, and vomiting. These symptoms made me want to stop the treatment. At work, these caused me trouble. I had to stop my work and rushed to the toilet because of onset of diarrhoea. My colleagues thought I was weird. They thought I might take drugs so I looked abnormal. It's impossible for me to tell them I am HIV positive. At that time, I had treatment interruption for 3 months…Then the HIV specialist called me back. I started to continue the treatment. This is my second regimen. Again, when I just started, I experienced similar side effects as the first one. It lasted for a month, and then my body adapted to the regimen afterwards."* (P14, MSM, 36y)

"*It's unnecessary to take these harmful medications. I was really against the treatment before, but now I have accepted it. Like when I just*

started the treatment, I lost a lot of weights. Before then I was 58kg. I thought I might add more fat to my body. Who knew that after taking it I would lose weight?! I really cared about losing weight, and this had influenced my medication taking." (P4, MSM, 26y).

By and large, it seems that perceived stigma related to HIV infection and feeling of shame carrying HIV status can decrease individuals' sense of self and their readiness and willingness to accept treatment and take it publicly. Additionally, the distinctive appearance of HAART and its effects on participants' body image is also a source of stigma. With visible body signs, it intensified some participants' feeling of shame and self-stigma, and feeling of vulnerability when interacting with other people. Such collective disruptions had negatively influenced many participants' medication taking, leading to treatment interruption.

6.2.2.1.2. Non-disclosure of HIV status

The previous sections have discussed the impact of social values on participants' emotion and interpretation of HIV. With this in mind, it implies that participants' emotion and perception could be viewed as interactional rather than just individual, which tied them into a social context (Yang et al., 2007). Living in the Taiwanese society where the image of HIV is negatively portrayed, most participants felt afraid and insecure to disclose their HIV status. This imposed limitations on them and created a barrier between self and others. As a result, not disclosing HIV increased participants' emotional burden and negatively affected their management of HIV and HAART taking.

"*I don't know. It's just not good. It is a shameful disease. I don't want to let my dad know. I just don't want to let him know.* " (P16, Male heterosexual, 42y)

"*Once my HIV was confirmed, I was anxious and wouldn't dare to tell my family. I secretly took it. Because I am an adult, I should take the responsibility of the consequence.* " (P9, MSM, 35y)

As discussed in **Chapter 3**, 'identity' is developed through self-construction of meanings and that self-meanings are influenced by social values (Goffman, 1963, Stryker and Burke, 2000). The link between one's self-identity and behaviour is bridged through the shared meanings (Stryker and Burke, 2000). The notions are coherent with participants' stories in which their act of not disclosing their HIV status was linked to the meanings they constructed within the Taiwanese society. Two reasons emerged from the analysis, illustrating their concerns regarding non-disclosure of their HIV status — maintaining relationships and defending self from social threats.

> ***"****I was afraid people would view me differently. I wouldn't dare to tell my family.* " (P12, MSM, 35y)

> "*Now it is a chronic illness, but you have the virus. You find it hard to confess. Actually, it is really hard. At the beginning of the relationship, I couldn't disclose. Because after I decided to disclose, they* [his previous partners] *left. Most of them chose to leave. Usually, there was no happy ending*." (P9, MSM, 35y)

The recurrent sub-category, non-disclosure, in the interviews conveyed a sense amongst participants that they wanted to maintain secrecy to avoid negative evaluation and hurt feelings. Aside from the fear of discrimination, the excerpt, "*Most of them chose to leave. Usually, there was no happy ending*." from P9 indicated that his previous experience of being rejected seemed to intensify his negative perception of HIV and affected how he handled situations relating to HIV disclosure. Not only can other's reaction towards the identity claims influence the affected individual's acts, but also whether HIV positive identity is incorporated into sense of self can (Stryker and Burke, 2000). In 'fear' of people's discovery of HIV status and/or negative reactions, many tended to avoid such potential risk by not taking HAART regimens openly.

"*Not many people would take the medications openly. To me, I cannot do it. I will try to avoid the risk. I've never taken my medications outside."* (P1, MSM, 28y)

"*People don't know my condition and I need to conceal. I just don't want to explain what medications I am taking to others*." (P18, Female heterosexual, 32y)

In short, by not disclosing HIV status to significant others, it seemed to have brought additional stress to participants and increase the challenge of building confidence to manage HIV and HAART.

6.2.2.2. Integrated self-identity

During the process of narrative re-construction, participants' integration of HIV identity into their sense of self has assisted them in viewing their HIV status more positively and/or in being more resilient. It also appeared to enable them to be more motivated and willing to face and manage HIV and HAART. Three key aspects were identified to help participants to develop their integrated identity: Accepting HIV status, selective disclosure of HIV status, and feeling supported.

6.2.2.2.1. Accepting HIV status

In face of living with HIV and HAART, it seems understandable that participants could develop negative emotions and might not fully accept their new HIV positive status. It is evident from the data that self-acceptance is an active process that involves participants' readiness and willingness to experience and face their HIV and emotions towards it, and incorporate it into their identity. Congruently, Pierce (2003) contends that psychological aspects of ownership can play a dominant role in owner's identity. The growth of psychological ownership provides positive and uplifting effects and facilitates a close connection between the individual self and the object experienced (Pierce et al., 2003). In this study, many took time to adjust their emotions towards HIV and to accept the new HIV status. Data presented below show participants' emotion process during their HIV trajectory.

"I started to use drugs when I was the 20s. At that time, I wasn't mature enough. I didn't know how to protect myself. So now I had this irremovable label with me, HIV…Upon diagnosis of HIV, I had low self-esteem. I had negative and self-destructive thoughts. I thought that why my life was so awful. I started to live my life in a self-destructive way. But it was the beginning. At that time, I was using MDMA. Then After I used amphetamine, I started to see through my life with HIV. Because amphetamine sensitised my sensations, it let me see myself and the surroundings clearly. Then I got to face HIV and accept it." [Later in the interview, he stated] "*In the past, when I used MDMA, I felt happy. That's why I kept using it. Then when I used amphetamine, I only used a small amount of it with my friends. It gave me a pleasurable sensation, making me feel great being with sex partners. I couldn't stay away from the drug dependence. To quit it, I decided to use a large amount of it, making myself feel unhappy. Then I developed hallucinations and behaved weirdly. Whenever I wanted to use it, I used a lot, making myself feel unhappy…It was hard and suffering. I had a fight with myself internally every day. In the end, I quit it by forcing myself to engage with external stimuli. Now I really cherish what is surrounding me. Getting on a train and listening to people's chats and voices…It took me 7-8 months to quit drugs, get back to normal lifestyle, and let my viral load be undetectable*." (P7, MSM, 30y)

"[When asking him about how he comes to terms with his HIV status, he said] *I have gone through everything. It's important to be positive. In this journey, my family was there. And partners. But I didn't really value partners. I think it still depends on self. Even though they were there for me I could still fall apart.* " (P4, MSM, 26y)

P7's account presented above indicated that at the beginning of HIV trajectory he perceived the new HIV-positive status negatively, and such negative thoughts and emotions influenced how he managed his life with HIV. Once he came to term with the HIV-positive identity, his self-acceptance

facilitated his development of values of living with HIV, and determine his subsequent acts of quitting drugs and optimising health outcomes. In light of P4's account, his self-acceptance of being HIV positive also appeared to involve process and his experiential learning. Through self-reflecting on his own HIV journey and finding meanings attached to his life with HIV, he was able to move forward. These views give agency to the individuals where individuals' acceptance of a new identity relies on the integration of their past, present and into future of the self that provides meanings and purposes (Williams, 1984). Individuals with coherent identity are more likely to perform a behaviour that can repair the discrepancy by altering the situation or creating a new situation (Stryker and Burke, 2000).

While some needed time to adjust and adapt to new HIV identity, there were a few who accepted their HIV status upon the diagnosis.

> "*I always used amphetamine while not wearing condoms. From the very beginning, I was already mentally prepared for it. Since I started to use it, I have known that I cannot quit using amphetamine. Moreover, I thought HIV is just a chronic illness. I didn't have much reaction. I was prepared for it, and thus I felt fine. I think the sickness is not in people's HIV itself but in their psychological part.*" (P21, MSM, 35y)

> "*Psychologically, HIV doesn't affect me. I already knew that getting HIV was unavoidable if I kept engaging in drugs and sex. Of course, I didn't want to get it. But when I lied on the bed, I have already accepted it.*" (P3, MSM, 37y)

> "*After I broke up with my boyfriend, I started to engage in promiscuity. I wasn't surprised that I got HIV. I loved bareback [sex without the use of condoms]. I wasn't surprised."* (P6, MSM, 52y)

Participants' self-acceptance conveyed a sense that they accepted the fact of being HIV positive rather than trying to deny or disown it. The narratives showed above, "*I was mentally prepared for it*" (P21, MSM, 35y), "*I wasn't surprised that I got HIV. I loved bareback*" (P6, MSM, 52y) and "*I already*

knew that getting HIV was unavoidable" (P3, MSM, 37y), illustrated that they acknowledged the possibility of getting HIV through risky sexual practices. Their acknowledgement and emotional acceptance prepared them to accept their HIV status. Data also revealed that unprotected chemsex involved not only negative consequences (e.g. HIV transmission) but benefit outcomes (e.g. sensation stimulation). Participants' sensation seeking increased their engagement with unprotected chemsex without regard to potential negative consequences.

On the other hand, participants who were in denial of HIV status appeared to less expect their chance of getting HIV (**Section 6.2.1.2.1.**). P3's statement —" *of course I didn't want to get it, whereas I have accepted it*" indicated that regardless of whether he found HIV pleasant or not his self-acceptance means accepting the true reality of being HIV positive. Whilst such reality cannot be changed, the data presented below show that P19 and P22 were able to accept HIV status which they might dislike, and to live with it with a positive attitude.

> "*In the past, it was called a black disease, but now it is a chronic disease. Compared to cancer patients, who know they will die first or us. This is the fact which cannot be changed. Rather than being depressed, I would rather happily lead my life.*" (P19, Male heterosexual, 43y)

> "*It's about our psychological part. In the past, people called it a black disease. Years later, it is now just a chronic disease. Living with it and letting it be part of me.* (P22, Male heterosexual, 52y)

The findings are congruent with Karnilowicz's (2010) notion that the new identity is integrated into one's sense of self when it is orchestrated in one's own way rather than motivated by external forces. By accepting the emotions towards their HIV identity, some participants were able to put themselves in a position where they can balance their negative emotions with positive ones and use the negativity in order to grow.

> "*Now I feel happy. I have changed my thought, thinking that if I wasn't infected with HIV, I could not have quit drugs*." (P19, Male heterosexual, 43y)

> "*The scar will be there with you for the rest of your life. It depends on how you view it. If I think it is a scar on my face, I wouldn't get along with it well. If I think it is part of my body, I would try to make it pretty or cover it up. It depends on yourself."* (P13, MSM, 31y)

Participant 13 used 'scar' as an example to describe the perceived negative label of his HIV-positive identity. His self-acceptance did not mean he liked what was happening but once he gave up the resistance and denial, he took the energy he was struggling and used it to manage HIV illness more wisely. His positive thinking and emotion adjustment seems to have turned the discrediting HIV illness into his strength. Congruently, Kralik et al. (2004) in his article on self-management of chronic illness maintained the importance of intellectualising the condition in order to alleviate anxiety, reconfigure daily life, and reconstruct self-identity. P19's and P13's' statements— "*Now I feel happy"* and *"it is part of my body"* indicate that by incorporating HIV identity into a sense of self they could recognise their value as a person and be happy being the persons they were, regardless of the HIV-related stigma. On one hand, data presented above provide an important insight into the impact of transition in cognitive thinking on emotion adjustment. On the other hand, by acknowledging and accepting emotions and realities, they also appeared to be more likely to accept the truth and think more rationally.

As a result of the integrated identity, participants were less likely to always emotionally dwell on the past and be more willing to advance forward and regularly take HAART.

> "*I already knew that HIV is a chronic illness a long time ago, which means that I should regularly take the medications. When I felt I was prepared*, *I would start the medications,*" (P21, MSM, 35y)

"*I don't know how I am feeling better. But I am just feeling better. It depends on whether a person wants health or not. Being healthy so that I am able to do many things*." (P22, Male heterosexual, 50y)

"*Now I am more proactive when it comes to dealing with things. In the past, when using heroin, I was very laid back. Now my life is changed. I think life shouldn't be like that. I lead my life proactively. To regularly take the treatment, I need to face it and proactively deal with it. Not harm myself and avoid things.*" (P20, Female heterosexual, 36y)

In short, instead of avoiding, self-acceptance appeared to provide participants with a chance to learn from the experience of living with HIV and HAART. In turn, it also enabled them to grow in its management and to integrate it into life.

6.2.2.2.2. Selective disclosure of HIV status

Self-acceptance and emotional stability have potentially strong psychological and behavioural effects, as a result of self-control, self-enhancing, invested efforts and social approval (Pierce et al., 2003). With such feelings of ownership, it can assist individuals in defining or re-defining themselves and expressing their self-identity to others. Within the data, it showed that participants' attempts to reveal HIV status could be the sign of seeking help and support. Such self-enhancing and seeking social approval could be viewed as self-identification.

"*I told my mum because I couldn't take it anymore. Then my mum knew it*." (P13, MSM, 31y)

"*I was really down. I told my family that I was under arrest and had committed many crimes. I was also sick [HIV].*" (P20, Female heterosexual, 36y)

"*I was pregnant, and thus I needed to tell him. He accompanied me to the hospital and accepted my HIV status. He doesn't have HIV*." (P10, Female heterosexual, 33y)

The excerpts from P13, P10 and P20, "*I couldn't take it anymore*", and "*I needed to tell him*", reflect that they were able to communicate the issue with their significant others in an attempt to share the burden and gain support. With the support from the significant others, it seems to enhance participants' sense of self and self-acceptance.

> "*I am glad that I didn't have a fight with my family for too long. I thought why I previously made a lot of efforts to hide my HIV status. I feel thankful that my parents accept me. Although the situation wasn't good by the time they just knew my HIV status, I am happy with the result now. I feel being in this family is good."* (P12, MSM, 35y)

In line with P12's experience, P7 had experienced family's rejection at the beginning of HIV and HAART trajectory. Nonetheless, such negative reaction from significant others did not last; rather their families got to accept and support him afterwards.

> "*I told my family about this [HIV]. They accepted it. They all knew my conditions. They also knew I used amphetamine and how much I used. They all knew. They were really angry at the beginning. But now they are fine and happy about my current conditions and forget about my past wrongdoings…At the beginning, me and my family were like enemies to each other. Now we are like friends. This is family*." (P7, MSM, 30y)

The data presented so far provided an insight that participants' disclosure of HIV could increase their chance of obtaining support and maximising their support resources, though they might experience stigmatisation at some points. By contrast, as discussed in the previous sections of this chapter, without disclosing their HIV status, some encountered the difficulty of handling HIV, HAART and illicit drug use, thereby they found it hard to manage overpowering emotions towards difficult situations, and experienced high levels of perceived stigma.

Being accepted and supported by significant others may not always be the case following disclosure. However, some participants strategically disclosed their HIV status to particular people who they trusted and were able to gain support from them. Based on the data, two discrete factors were taken into consideration by participants when disclosing their HIV status— the persons they disclosed it to, and how they disclosed HIV. The persons they chose to reveal their HIV status were often the ones they were close to and were less likely to discriminate them.

> "*My aunt is open-minded. I feel thankful that I have my aunt. I was raised by my grandmother. When I just learned my HIV status, I didn't have the courage to tell my grandmother. Instead, I told my aunt…She didn't blame me. After telling her, I can openly be myself as an HIV-positive gay man.*" (P1, MSM, 28y)

> "*You cannot be too open to your colleagues. Be nice to them, but I still keep my privacy. Maybe people will talk about my HIV and gossip.*" (P09, MSM, 35y)

The way participants strategically disclosed their HIV status optimised their chance of being accepted by significant others.

> "*I would chat with him first and then educate him about the correct knowledge of HIV. At the very beginning of hearing the word, HIV, his reactions were against it. Then I told him that not all of the HIV-positive people contracted HIV by promiscuity. The transmission route of HIV can be through blood. I kept educating him. Then, in the end, I told him I am HIV positive. His reactions changed from feeling uncomfortable to feeling fine with this illness.*" (P10, Female heterosexual, 33y)

> "*I told them that I haven't got a cold for two years, and they said oh yes. I used this method to let them accept. I educated them to view HAART as medications for treating a cold, not letting me get a cold. My parents quickly accept my HIV status. I feel grateful.*" (MSM, 35y)

Participants' adaptation is, in part, a function of self-identity, in which individuals attempt to create and maintain their sense of self by altering the situation that helps infuse roles with personal meanings (Stryker and Burke, 2000, Pierce et al., 2003). This is exemplified by P1's narratives— "*After telling her*, *I can openly be myself as HIV-positive gay man*"— presented above. P1 was able to create positive change by disclosing his HIV status to his trusted aunt, contributing to enhancing his sense of self as an HIV-positive gay man.

According to participants' statements, after disclosing HIV status to someone trusted and being supported, participants were more likely to feel at ease and secure when managing HAART use.

> *"Now my partner and my friends already knew my HIV status. I don't need to hide, and thus I am not afraid… I sometimes asked my partners and close friends to remind me of taking the medications."* (P10, Female heterosexual, 33y)

> "*When I told my sister about my condition, she was very considerate, gave me support. This medication can cause me to feel dizzy. With their support, I don't need to make excuses for why I am dizzy.*" (P21, MSM, 35y)

In summary, participants' strategic disclosure of HIV-positive identity to significant others appeared to open up an opportunity for gaining support and reduce the possibility of being rejected. In turn, such disclosure also decreased their levels of stress and anxiety that might overwhelm them, enhanced their internal strength to self-acceptance, and facilitated their ability to manage HIV and HAART.

6.2.2.2.3. Feeling supported

As discussed in the **Section 6.2.1.4.**, "looking to outside people" should not be viewed as the only source of support. Participants also needed to become the source of support themselves. With the feelings of being loved, valued, and secure while receiving support, participants appeared to be more likely to

develop a sense of self-esteem, self-respect, and self-identity. That is what it means feeling supported in this study.

> "*When I saw my mum's full support. I knew that my mum loves me. My mum's boyfriend also treats me like his son. It makes me feel like at home. Although I am not perfect and I used drugs, after quitting drugs, I want to enjoy living at home. For my family, I want to do well. I want to live. If I don't regularly take medications and then get sick, they will be sad. I want to take care of myself. Let them see that I am good and happy*." (P13, MSM, 31y)

> "*During this process, the HIV specialist always encourages me. I can feel the support. I feel thankful. I will bravely keep moving on. I need to take the responsibility of my life. Although it is painful to have HIV, this medical team is my only motivator to move forward.*" (P2, MSM, 32y)

The participants' narratives presented above illustrated that their feeling of being loved and cared by family and health professionals enabled them to feel and think that they mattered, thus increasing their motivation to get well. In its fundamental sense, data revealed that feeling supported could also provide a sense of connectedness to others—to family, to friends, and to the community.

> "*In this association, they accept me. It's like there is no distance and gap between us. Here they all know I am HIV positive. I can reveal my HIV status in front of them.*" (P8, Male heterosexual, 49y)

> "*Our family is quite close. I initially only told my sister. Then later on my family started to discuss how to help me to go through it. They took me to a hospital for refilling the medications without showing their worries*." (P14, MSM, 36y)

In light of the sense of connectedness, it is evident within data that participants who felt supported were more inclined to think that there was a safe place in the society where people cared about them, where they were

respected, and where they were able to get help to work out any problems. Stryker and Burke (2000) proposed that the relationship and connectedness with others can enhance the incorporation of the salience of an identity into the self and provoked the behaviour choices in accordance with the expectation attached to that identity. The excerpts presented below— "*You know how I know.that's when feeling secure*…" and "*I can see…I feel thankful*.." conveyed P12's and P13's sense of connectedness with others and such feelings facilitated incorporating HIV-positive identity into their sense of self and subsequent HAART taking.

> "*You know how I know they started to accept me [family]?! That's when they remind me to take medications. It was a big encouragement. They want me to live." [Later he also stated] "Not only my family know my HIV status, but also my colleagues do. I want to stay in this company for the rest of my life. Do you know when people will settle down? That's when feeling secure, and then they will settle down.*" (P12, MSM, 35)

> "*The HIV specialist's support has positively impacted my medication taking. Every time I came to the hospital, I would visit the HIV specialist. I would mindfully tell myself to visit her. Because I can see how hard she tries to assist us in taking medications. I feel thankful.*" (P3, MSM, 37y)

With the feelings of being respected and cared for, it helped participants to enhance their self-esteem and sense of purpose in life. It is exemplified by participants' stories:

> "*I started to use drugs after I got HIV. Previously, I was controlled by amphetamine. My thoughts were very extreme. I was fighting with my boyfriend all the time. I even carried a knife to scare my boyfriend's family. I ran away from my boyfriend's place and called my dad that I wanted to die. My dad called police and tried to find where I was living. They found me in a hotel. I was naked at that time, and kept saying that I wanted to kill myself. They took me to a hospital. I went crazy. I was*

screaming and destroying hospital's stuff. I was put in a security room. I didn't have that part of memory. My mum told me I was using diapers at that time. My dad even helped me to change my diapers. My mum said my dad cried a lot [sobbing]." [Later he added] "*When only me dealt with the situation, I was very negative. Thinking that HIV is not curable and why I should take medications. I would rather just enjoy my life do whatever I wanted. That's why I started to use drugs. After my family knew my situation, they made me not have negative thoughts and not have the thought that my life is meaningless."* (P11, MSM, 31y)

"*This wife is the one I get married recently. She accepts me. My life has been changed and she can see it and was willing to marry me*." (P8, Male heterosexual, 49y)

When it comes to enhancing 'sense of self-esteem' and 'sense of self', these seemed subtle when looking at the data, but it can be felt when deeply engaging with the data. P13 and P8's statements, '*they treat me well*' and '*they accept me'*, and P11's heartfelt experience of family's support (when describing how his family helped him to go through the process, he was sobbing), were in a sense that they could feel they were being cared, accepted, and respected. With more strongly committed identity, an individual's ability to perform well was greater (Stryker and Burke, 2000). This is evidenced in the excerpts from P8 and P13— "*My life has been changed*", "*I want to do well*", and "*I want to live*", which conveyed their positive feelings of living in this world and their life aspiration.

As with feeling supported by family and health professionals, a personal relationship with God was stated by some participants to provide a source of comfort in their troubled times, as well as a foundation for feeling unconditionally valued, loved and cared for.

"*In the past, I believed in Taoism. I couldn't accept Jesus. After I went to rehab, I got a chance to read the Bible. A pastor also came to deliver God's messages. I used to be a shaman [Worked to connect with*

spirit.]. I got to realise that why previous me always harmed myself. Love isn't supposed to be like that. In Christianity, I got to realise that, especially as I feel accepted, wow, it is phenomenal. Without God's mercy and grace, I don't think I can move on. I feel thankful." (P8, Male heterosexual, 49y)

"*I have lost so many things, and I got HIV. I didn't know how long I could live. I felt resistant to accepting the realities. Then one time one pastor came visit me and delivered messages which were very touching. I started to take his class. This pastor was always there to be with me. We weren't family but he didn't charge me for the class fee, gave me food and a place to stay. It is faith, sense of belonging. I have done so many wrong things* [Earlier in the interview, he stated he has done *"cheating, robbery, killing and stealing"*]*, and now it is the opportunity for me to change and live in a different kind of life and at a different stage of life. Faith gives me a sense of belonging."* (P19, Male heterosexual, 43y)

Based on participants' statements below, not only faith provided them with a sense of security and belonging, but it gave them peace and calm, and helped them to find hope, meaning and purpose in life and at difficult times. The positive impact of religious support on participants' inner part seemed to have helped them to re-establish their value and belief system and strengthen their will to live meaningfully

"*Now I am calmer. In the past, I couldn't be calm. I was very impulsive. I don't know why I feel peace and calm after I was baptised. Then I started to take the cocktail treatment.* [In the interview, he talked about his background] "*Going back to my previous path would involve illicit drugs, gunshots, stealing, and killing. This kind of path…Our family is different and not like a normal family. Our family is a gangster family. When having a family gathering, there would be me and many of my subordinates.*" (P5, Male heterosexual, 45y)

"*In prison, I wanted to kill myself and there was no hope. It was a really low moment for me. However, there I found God. It was like changing from feeling of desperation to feeling of hopefulness. I had hallucinations at that time, but after praying for 6 months they were all gone. It was like God's love touched me. He forgave me and redeemed my sins. When I was released from jail, I forgot I have a husband because of my full enjoyment of being loved by God. My family told me if I wanted to see my husband. He was at the prison at that time. I said oh my. Then I started to write him letters and pray for him. One time I studied Bible and saw God's Word—What God has joined together let no one separate. I felt God didn't want me to give him up. Then after he was out of jail I told him I am HIV positive and asked if he still wanted to be with me? He chose to be with me.* [Field note: Both of them are in sobriety now and remain in marriage]" (P20, Female heterosexual, 36y)

"*People need religious faith. I told one of my friends who I have known for 8 years while I was still using drugs. He took me to a church. We sang at the church. It made me realise the importance of not fearing stepping outside the drug circle and the importance of interacting with people. This faith has greatly influence my regular use of medications.*" (P4, MSM, 26y)

As a consequence, participants' statements presented above— "*If I don't regularly take medications and then get sick, they will be sad. I want to take care of myself. Let them see that I am good and happy"* (P13, MSM, 31y), "*That's when they remind me to take medications. It was a big encouragement. They want me to live*" (P12, MSM, 35y), and "*This faith has greatly influence my regular use of medications*" (P4, MSM, 26y) illustrated that by feeling supported and finding meaning in life it seemed to motivate them and facilitate their willingness to face HIV and manage HAART.

Taken together, the findings reflect that individuals' feelings of being supported and sense of connectedness can serve as a key mediating factor

in the emergence of self-acceptance and management of illness (Karnilowicz, 2010).

6.3. Discussion

This study showed that during the HIV trajectory, social stigma related to HIV and its impact on support system in the society (external influences) undermined participants' emotions and disrupted their self-identity reconstruction.

Drawing on the literature review in **Chapter 4**, stigma was the predominant theme identified from the included studies conducted in Canada, USA, Ukraine, Russia and India (Batchelder et al., 2013, Chakrapani et al., 2014, McNeil et al., 2017, Mimiaga et al., 2010, Rhodes and Sarang, 2012, Small et al., 2009, Ware et al., 2005). This implies that HIV-related stigma does not only occur in the developing countries but developed countries. In the same vein, in this study, participants lived in the Taiwanese society where HIV-related stigma is prevalent, making it increasingly difficult to cope with HIV and HAART. Subsequently, many had developed negative emotions upon HIV diagnosis. Crawford's meta-analysis (1996) indicated that the degree of stigma related to HIV is higher compared to the degree of stigma related to other health conditions, such as cancer, hepatitis, and leukaemia. Though other health conditions can be acute or lethal, yet those may not create the level of stigma as high as HIV does (Crawford, 1996). Drawing on the data, this can be explained by the association of HIV with other stigmatising attributes, such as drug use and homosexuality. Issues relating to its moral aspects seem to have made it more challenging to eliminate HIV-related stigma, gain support and integrate HIV positive identity into self-identity.

The impact of HIV-related stigma on HIV-positive individuals' psychological well-being and adherence to HAART has been documented in the systematic review by Katz et al. (2013). Comparing the general HIV population with HIV-positive drug users, the difference lies in the fact that drug users not only need to deal with antiretroviral treatment but drug use problems. HIV-positive

drug users in this study tended to experience emotional difficulties, and avoid facing HIV as part of themselves by heavily using illicit drugs, especially when they found emotions were too difficult to handle. Their emotions towards HIV and perceived meanings attached to it led to biographical disruption and influence the process of self-identity re-construction (Bury, 1982).

Self-identity is an ongoing constructing process whereby the individual develops and forms a sense of self through personal experience and social interactions (Karnilowicz, 2010, Stryker and Burke, 2000). The participants' negative self-perception towards HIV appeared to be deeply grounded in social values, which could disrupt the integration of HIV-positive identity into self-identity. By possessing HIV identity, some felt ashamed of living with it. Their feeling of shame had created a barrier to accepting HIV status and viewing it as part of the self. In turn, this led to an unwillingness to take HAART regimens publicly or disclose HIV status in fear of people's discovery and rejection of them (**Section 3.3: discreditable**). In addition, participants' concerns over the distinctive appearance of some HAART medications and their side effects on change in body image emerged within the analysis to also affect their HAART taking (**Section 3.3: discredited**). Data demonstrated that the visible signs that exposed HIV-affected participants to the risk of stigmatisation even intensified their fear and perceived stigma.

On the other hand, accepting HIV status, selective disclosure, and feeling supported were revealed to facilitate keeping participants' emotions in control and integrating HIV-positive identity into sense of self. Participants with a coherent sense of self appeared to think more rationally, and be more resilient. Participants' selective disclosure of HIV status is in a similar manner to the concept of "mobilising resources" in Bury's (1982) biographical disruption, which can be viewed as part of self-identity re-construction (Stryker and Burke, 2000). This study showed that self-disclosure increased the chance of gaining support. Having support at hand and feeling supported helped to alleviate participants' emotional burden while coping with HIV and

HAART, and to develop a sense of connectedness to people and the environment. With the sense of connectedness, they were inclined to feel valued and secure of living in this society and taking HAART regimens. In other words, participants' feeling supported facilitated their adaptation of negative emotions, integrating new HIV identity into their sense of self, and developing positive thinking towards life with HIV and HAART.

Participants' self-identity re-construction involved the process of emotion adjustment and transition in thinking. This process required participants to integrate the past self into present self and towards the imagined future which provides them with a sense of unity and purpose in life (Williams, 1984). It was evident in this study that the process was not linear but dynamic. Some participants accepted their HIV status without going through difficult emotions, but others experienced emotional difficulties and felt no motivation to live or accepted themselves as HIV positive afterwards. Resonate with the findings, it has been proposed by Kralik et al. (2004) that individuals' narrative is in the form of self-management that relies on affected individuals to accept the illness, adapt to the change, and have control over its effects.

CHAPTER SEVEN: VALUES ATTACHED TO HAART

7.1. Introduction

Developing on the concept of HIV-positive identity as part of self-identity, the concept of values attached to HAART emerged as central to participants' HAART-taking behaviour. In this study, the degree to which participants held their value of HAART greatly influenced their motivation and engagement with HAART taking. Throughout this chapter, the term value, here, refers to participants' deep-seated belief in the importance of regularly taking HAART. Value development involves participants' thoughts and feelings regarding HAART taking through the interaction of personal and social experience. Despite this concept emerged within the data, so far, there is a paucity of literature focusing on the theories relating to values (inner aspect). In addition, very little attention has been paid to the role of values in an individual's health behaviour. Therefore, in this chapter, few existing theoretical literature is discussed when incorporating literature into findings.

This chapter begins by laying out the proposed theoretical dimensions of participants' value attached to HAART. Then, it proceeds to discuss how the values participants placed on HIV and HAART ignited/undermined their HAART-taking. The properties of the concept, values attached to HAART taking, are summarised in **Table 8**.

Table 8: A summary of values construction

Concept	Category	Sub-category
7.2. Values attached to HAART taking	7.2.1. Lack of values attached to HAART taking	7.2.1.1. Forming negative assumptions about HAART
		7.2.1.2. Not perceiving the importance/need of and disinterest in regular HAART use
		7.2.1.3. Placing values on drugs more than HAART
	7.2.2. Developing the values of taking HAART	7.2.2.1. Perceived benefits of HAART taking and perceived severity of erratic HAART use
		7.2.2.2. Having life aspirations
		7.2.2.3. Developing the mindset of valuing HAART taking

7.2. Values attached to HAART

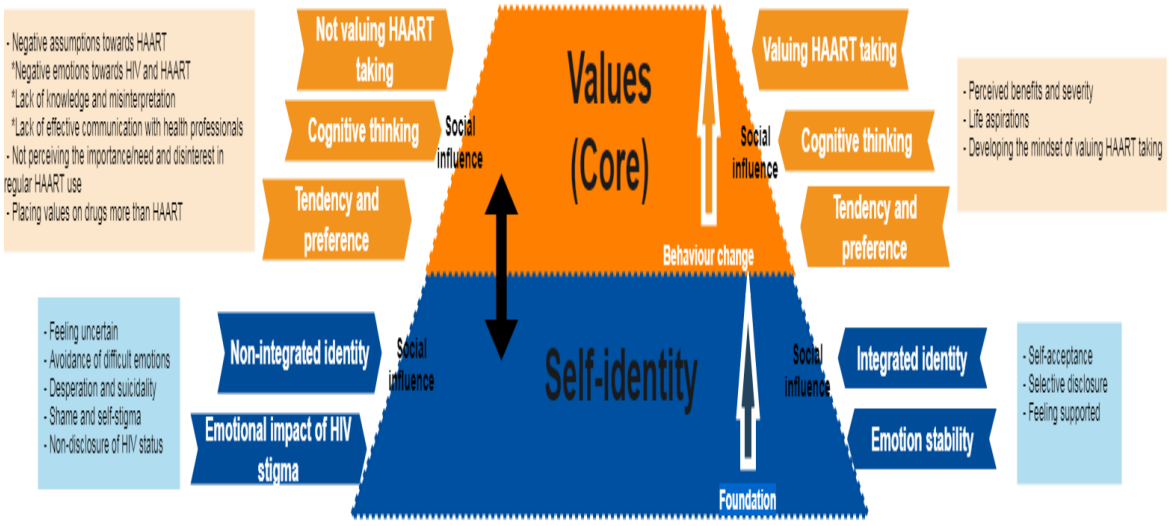


Figure 9: Self-identity re-construction and values attached to HAART taking

Figure 9 presents that participants' integration of HIV-positive identity into sense of self can lay a foundation for the development of values attached to HAART taking. In this study, participants' experiences of HAART-taking was centred around what they valued. The values participants placed on HAART was rooted internally and deeply in their belief system, wherein they attached meanings and purposes. To understand participants' experiences of taking HAART, it is essential to gain further insight into their values with regards what they thought and believed to be important in their lives (**cognitive thinking**) and where their interest laid (**tendency and preference**). This facilitates understanding what drove and directed their HAART taking.

7.2.1. Lack of values attached to HAART

From the data, it appeared that developing values of HAART involved individuals' perception of its importance, provoked motivation, cultivated their interest in investing time and efforts in it. However, some participants appeared to not hold a value of HAART and make it worthwhile doing. The key aspects of their lack of values attached to HAART are listed as below: Forming negative assumptions about HAART, not perceiving the

importance/need of and disinterest in regular HAART use, and placing values on drugs more than HAART.

7.2.1.1. Forming negative assumptions about HAART

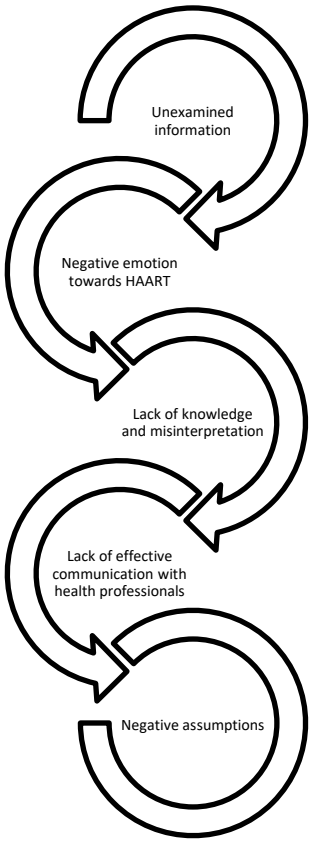


Figure 10: Interplay behind participants' formation of negative assumptions

At the initial stage of HIV diagnosis, some participants appeared to not fully understand HAART. In need of filling in informational gaps regarding HAART, the extracts from participants shows that there was unverified information (**Figure 10: Unexamined information**) circulating in their drug circles and few had believed it before starting HAART. In turn, it shaped their opinions about HAART.

> "*At the first two weeks, I was struggling if I should go seek medical care. Because some people told me that there was no need to take the medications and without taking medications, HIV could still be controlled very well*." (P12, MSM, 35y)

"*Most people are afraid of facing HIV and the treatment and are afraid of change. We have heard a lot in our circle that there are many side effects of cocktail treatment. Many rumours. The rumours spread around in our circle. It made them fear to change and receive treatment. Same as them, in the past, I didn't want to take the treatment because of that. I couldn't make a decision, and thus I kept staying in that circle. It wasn't necessary to take the medications that could harm my body. It wasn't necessary to take such harmful medications*" (P4, MSM, 26y)

"*When I saw other people took cocktail treatment in jail, I would think they might die soon. I have heard a lot about its side effects in jail. This made me afraid of receiving treatment*. *After taking the treatment, I feel fine. Nothing happened.*" (P20, Female heterosexual, 36y)

P4 used the word 'rumour' to describe the information that was in circulation in their circle of drug friends. P12, P4 and P20's narratives illustrated that as they took the information that they saw and heard into their cognitive process, the information was interpreted, and the unexamined information formed their negative assumptions about the need for taking HAART. In Oxford dictionaries, 'assumption' is defined as something that is taken for granted and is accepted as true without proof (Oxford dictionaries, 2017). By choosing to believe the negatives of HAART, it has heightened the levels of P12, P4, P20's anxiety about receiving HAART (**Figure 10: Negative emotion towards HAART**), and influenced their decision of access to HIV care. Participants' negative assumptions towards the side effects of HAART resonate with the concept of perceived barriers, proposed in the HBM, wherein an individual's perception of barriers to health or health behaviour can hinder his/her performance (Becker, 1974, Janz and Becker, 1984, Rosenstock, 1974a and b). Furthering the notion of perceived barriers, Marshall and Biddle's (2001) and Hall and Rossi's (2008) meta-analyses of examining the effectiveness of the transtheoretical model on examining people's health behaviour showed that at the pre-contemplation stage individuals were more likely to think of the cons of performing health

behaviour, consequently influencing their behaviour. Similarly, as shown in the data, participant's negative assumptions of HAART and feelings of anxiety tended to occur at the beginning of their HIV trajectory, resulting in influencing their decision to take the treatment.

According to P5 and P14's narratives shown below, it pointed that the unexamined knowledge regarding HAART was widespread in their friend circles, which had influenced many of their peers' decision to receive HAART.

> "*I have heard many people said that. I don't know if it is true. They said that there is no need to take cocktail treatment. It is fine to keep injecting drugs. Injecting drugs can increase CD4 cell count. A lot. Many people believed that.*" (P5, Male heterosexual, 45y)

> "*I have a friend who is HIV positive and a drug user. He doesn't receive anti-HIV treatment. He has used drugs for 30 years. He is HIV positive, but he isn't willing to receive the treatment. In this circle, some people's thoughts are so advancing. I thought how come he can still live such long. He never receives treatment. Also, he uses a lot of drugs. According to his statements, he has been using a health product from his company and this product can give him energy. He said this is the key to maintaining health. We were almost influenced by him. It sounds magical. Once a day and 4 pills at a time. It might have influenced many people.*" (P14, MSM, 36y)

What participants chose to believe played an important part in their interpretation of HAART. For example, P4 and P14, at the beginning of HIV trajectory, were in denial, avoided their HIV specialist, and used drugs (**Section 6.2.1.2.1.**). Their lack of self-acceptance as being HIV positive, lack of knowledge and its emotional impact had influenced their decision-making tendency towards the rumours of unfathomable knowledge of HAART. This implies that poor psychological state could influence a person's rational

thinking and decision making (**Figure 10: Misinterpretation and lack of knowledge**).

Participants' negative assumptions towards HAART were also affected by the lack of effective communication with health professionals (**Figure 10**). Health professionals play an important role in educating patients and delivering correct information. Nonetheless, few participants brought up their unsatisfactory interactions with physicians in which information was not communicated as desired.

> "*My physician didn't force me to start the treatment but suggested me to take it. At that time I still felt resistant to starting it. Now my CD4 is increased to 600. If he told me to take it earlier so that my CD4 cell count could increase even more, I would have done so. While my CD4 is fine, I still prefer to have it higher. Maybe it was because of ineffective communication.*" [Later in the interview he added] "*They didn't tell me more. Maybe because they weren't taking the medications, they wouldn't think what situations or consequences we might encounter. In fact, what we encountered is much more complex and broad. This could affect our regular use of the medications. This is how I feel*." [In terms of his feeling of resistant, earlier in the interview, I asked him what he thought about HAART after the diagnosis of HIV and he said] "*Firstly, I didn't completely accept it, secondly, I didn't completely understand it, and thirdly I didn't want to know it.*" (P13, MSM, 31y)

> "*I told my physician that I have lost a lot of weight. I asked if it was because of the side effects of the medications. He said it was impossible and this type of medications didn't have such a side effect. Then I thought why I kept losing weight. I told him and he said it was impossible. Then what should I do? I kept losing weight. So I thought if I skipped doses for three weeks I might gain weight. But I didn't gain weight after three weeks*." [Field note: After the interview, he told me his physician arranged abdominal ultrasound next week.] (P17, Male heterosexual, 37y)

The excerpt from P13 and P17— "*I told him and he said it was impossible*" and "*they wouldn't think what situations or consequences we might encounter*" pointed that health professionals did not identify concerns of theirs and educate them accordingly. Without the knowledge of HAART, participants were less aware of the importance of taking it, in turn, this has formed participants' own interpretation and assumption about the need for taking HAART (**Figure 10: Negative assumptions**). In addition to lack of informational support, P13's extract showed that his emotion was not stable at the beginning of HIV trajectory, and he did not want to know HAART. His negative emotion and lack of readiness influenced the amount of information he could absorb.

Taken together, it was evident that some participants tended to hold negative assumptions towards their HIV status and HAART, especially at the beginning of HIV trajectory. Such negative assumptions were revealed to be linked to their lack of knowledge and misinterpretation of HAART. Participants' negative emotion and the lack of effective communication with health professionals were found to play a mediating role in their processing and interpretation of information relating to HAART. Congruently, drawing on the empirical evidence discussed in **Chapter 4**, the results also showed the strong linkage between drug users' level of knowledge relating to HIV and HAART and their relationship with health professionals and engagement with healthcare (Chakrapani et al., 2014, Pach III et al., 2003, Ware et al., 2005). As a result, it was revealed in this study that participants' negative assumptions about HAART negatively influenced their willingness and motivation to receive HAART.

7.2.1.2. Not perceiving the importance/need of and disinterest in regular HAART use

Participants' lack of knowledge and negative assumptions towards HAART appeared to have an impact on their HAART-taking. Nonetheless, data suggest that acquisition of knowledge relating to HAART did not necessarily increase the values they placed on 'regular HAART use'. Low levels of

values participants placed on HAART appeared to have governed their state of motivation and HAART-taking behaviour. Such low levels of values of regular HAART use was shaped by the degree to which participants believed in the importance of regular HAART use. This notion is gradually unpacked throughout the section.

> "*Sometimes when I was sleepy, I would feel lazy to get up to take medications. I thought it was fine to take them next day. It doesn't happen frequently, less than 3 times a month. I don't care*." (P6, MSM, 52y)

> "*I had treatment interruption because I was laid back. Hence I didn't go to hospital…Also, at that time my CD4 cell count was fine, at around 500. I thought it was fine to stop the treatment*." (P16, Male heterosexual, 42y)

P6 has taken antiretroviral medications for 15 years and is a relative adherer (**Appendix 1**), whereas data showed that he intentionally skipped doses sometimes. His statements— "*it was fine to take them next day*" and "*I don't care*" indicates that skipping doses few times did not concern him. Congruent with P6, P16's statements— "*I was laid back*", "*CD4 cell count was fine*" and "*it was fine to stop the treatment*" showed that his CD4 cell count data, his own interpretation of the need for taking HAART, and his laid back led to low levels of value attached to HAART taking and treatment interruption for two years. In Rokeach's book (1973), *The nature of human values*, he contended that a value is a belief that involves personal perception of what is true or false, good or bad, and desirable or undesirable. In other words, values have cognitive, affective, motivational, and behavioural components (Rokeach, 1973) – A cognition that involves interpretation and develops a conceived value (e.g. "*I thought it was fine"*, P6, MSM, 52y), an affection that provides feeling about the object (e.g. "*I don't care*", P6, MSM, 52y), and a behaviour that is provoked when the value is activated (e.g. Skipped doses). These were shaped through the process of participants' experiences. When not

thinking and feeling the importance of taking HAART, participants were less likely to value it and to take HAART regularly.

Drawing on participants' narratives, their disinterest in regular HAART use conveyed the sense that there was no strong inclination towards taking HAART. By not perceiving regular HAART use as important and needed, participants were less inclined to invest time and energy in taking HAART. P13's narratives below illustrated that what is in his mind could set the direction towards which his motives and interest go.

> "*It all depends on personal "心態". [My note: in Mandarin, its meaning is the combination of heart and attitude]. If his "心態" is like it is fine to take it later. Then he would miss the dose*." (P13, MSM, 31y)

> "*I cannot take it too seriously. Now I have ruined the first line of antiretroviral drugs. Now I am using the second line of it. As a human being, we would sometimes seize opportunities to not take medications. I like to make excuses and take the opportunity of not doing things. This time I didn't take pills; then that's fine, I will take it next time. This is humanity... If I know this is the last chance, I wouldn't have missed doses."* [Earlier in the interview, he said] "*There are many temptations. When I used drugs and had fun outside, I wouldn't think of the time and my antiretroviral regimens.*" (P1, MSM, 28y)

The word "心態" (Hsin Dai) used by P13 is similar to the meaning of mindset. '心' means 'heart'; '態' means 'attitude'. Taken together, it refers to the attitude towards HAART is shaped by 'deeply valuing' it. Without having the mindset that can facilitate engagement with HAART taking, participants appeared to manage HAART in a disinterested manner. The word, "心態", was used by many participants throughout the interviews. Similar to the findings, Rokeach (1973) and Grube et al. (1994) described that as opposed to 'attitude' and 'belief', 'value' occupies a more central position within one's

cognitive system and personality makeup. An attitude is an organisation of several beliefs around a specific object, whereas a value is a single belief of a very specific kind (Rokeach, 1973).

Many participants articulated that they quit drugs and regularly took HAART because of the value they placed on HAART and subsequent development of mindset (**Section 7.2.2.3.**). On the other hand, participants who did not develop the value of regular HAART use were less likely to consistently follow medication regimens. It was evident in P1's narratives illustrating that by not perceiving the importance of regularly taking HAART he tended to be disinterested in it. Without valuing HAART, he appeared to make excuses for not taking it and rationalising his behaviour. As a result, the low level of a value he placed on HAART had directed his HAART-taking behaviour by not making much effort and time to engage with HAART taking. Instead, P1 tended to place his value on chemsex more than the treatment (**Section 7.2.1.3.**).

P3 and P15's narratives presented below showed that a low level of values and perceived necessity of regularly taking HAART could be born out of their personal experience in relation to their CD4 cell count and viral load. Without regularly taking antiretroviral medications, P3's and P15's CD4 cell count was stable and viral load remained undetectable, and therefore such results demotivated them to regularly take HAART.

> "*Sometimes I think it is fine to make up for it next day. Because over the past few years, my CD4 cell count has been stable. Even though I didn't take the medications for 10 days and then took them again for two days then not took them for 4-5 days then took them for 2-3 days again then not took them for another week, my viral load was still undetectable. I think it should be fine not taking the medications regularly. It becomes my excuse.*" [Later in the interview he said] "*Over these two weeks*, *I haven't taken the medications regularly. I got laid back. I couldn't find things that can make me regularly take the medications. Yes, I think it's*

motivation. Now it's like whenever I remember I would take them." (P3, MSM, 37y)

"*It doesn't matter. If I don't take my medications, it is fine. Now my health is stable. I would think it's fine to miss one dose, I can take it next day.*" [Later in the interview I asked him the impact of not regularly taking HAART, and he said] "*I don't know what would happen if I don't regularly take it. But every month I went checking my CD4 cell count and viral load. My viral load was undetectable. CD4 cell count was 300-400. Since I started the treatment, my CD4 never went up to 500 but it could be up to 490. Since I started the treatment, it has been around 300-400. But after I started using drugs again, it dropped to 200. Until now my CD 4 has never gone up much. I knew that if we initiated the treatment too late, it would be less likely to increase CD4 cell count.*" (P15, Male heterosexual, 53y)

To sum up, Rokeach (1973) maintained that values can undergo long-term changes, and the behavioural consequences are expected to follow from the change in value. In this study, participants' values appeared to be implicit, whereas they could ignite/undermine participants' motivation and HAART-taking. Some participants were equipped with knowledge. However, it did not seem to matter, if not being interested in investing time and effort in HAART taking and not perceiving it as important and needed. In addition, participants' experiences can also re-shape their perception of the need for regular HAART use.

7.2.1.3. Placing values on drugs more than HAART

The values participants placed on regular HAART use differed amongst participants. Illicit drug use was found to influence the values they placed on HAART in two ways— Hierarchy of values (personal preference) and the impact of drug effects on changing personal values. As discussed in the last section, P1 did not place much value on regular HAART use. Rather, his narrative shown below was in a sense that whenever he went out and engaged in chemsex, he would not care about his dosing times.

"*I often went out at midnight for having sex and using drugs. When having fun, I wouldn't think of dosing times. I wouldn't finish it within 3-5 hours. In our circle, people who use drugs care about sex. I don't like feeling time pressure. When having fun, we shouldn't feel pressured. Most of the people in our circle spend lots of time involving in sex and drugs*" (P1, MSM, 28y)

"*When I used drugs and engaged in sex [chemsex], I wouldn't take the medications sometimes. Drugs could keep me alert. I used all my energy for the sex, and thus I didn't regularly take the medications.*" (P2, MSM, 32y)

"*Some would just crave for that euphoric effect, and constantly inject drugs to sustain that kind of feeling…Then would neither care what time it was nor notice dosing times*" [Later in the interview, when talking about drug effects and its impact on access to care, I asked if methadone could help to alleviate drug effects and enable her to take medications] P18 said "*It is very rare. I know that some experienced withdrawal symptoms, and then drank methadone to alleviate the symptoms. So they could have the energy to find drugs. I've even seen people who drank methadone and injected heroin at the same time. Then became very addicted to heroin and methadone. Then. it would be very difficult to quit both drugs*." (P18, female heterosexual, 32y)

As with P1, P2 also appeared to prioritise chemsex over taking his HAART medications. In contrast to P1 and P2, some other MSM participants were able to regularly take HAART regimens while engaging in chemsex (**Section 7.2.2.1.**). By comparing the two groups, it was revealed that values play a key part in guiding the way they looked at HAART and governing their HAART-taking behaviour. By valuing life with HIV and HAART, participants were more likely to develop their mindset and regain control over their HAART- and drug-taking behaviour (**Chapter 8**). However, in the cases of P1, P2 and P18, they tended to place more emphasis on drug use more than HAART use in pursuit of its euphoric effects. This resulted in their erratic

HAART use. In light of Rokeach's (1973) notion of values, he proposed that a value represents one's preference. A person could prefer a particular end-state in comparison with others, leading to value hierarchy. Values can be in conflict, and thus when attaining one value, it can block another (Grube et al., 1994). Such hierarchical order of individual values steered sequences of acts (Rokeach, 1973, Schwartz and Bardi, 2001).

In addition to personal preference and choice, another concern was expressed by some participants regarding the effect of drugs on changing their perception of the importance of taking HAART. Such change in perception was stated by them to influence the values they placed on HAART and their engagement with HAART taking.

> "*When using a lot of drugs and for a long period of time, we would not have self-awareness. We wouldn't think of whether we needed to maintain health. I would feel why I should take the medications.*" (P14, MSM, 36y)

> "*Psychologically, I would feel it didn't matter whether I had taken the medications or not. Using drugs already means not caring about your health.*" [Later in the interview he added] "*Because using drugs could distort my values and my worldviews. They were all changed and distorted. I wouldn't care about my health.*" (P15, Male heterosexual, 53y)

In the discussion of the change in personal values, issues related to shifted focus and thought while using drugs was prominent in interview data.

> "*It is very rare that we could use drugs while taking cocktail treatment.*" [Later he added] "*Because drugs influenced the way I thought. It was like I couldn't live without drugs. My focus was about money and how I could steal and rob to get money. To me, I didn't even want my parents. I could play a game in an attempt to get money from my parents. I could also ask my closest girlfriend for money. It is impossible. If you don't use drugs, you won't be like that. That kind of thought was distorted. I*

was completely controlled by drugs. To be honest, I wasn't like that before I used drugs, and I knew how I should treat people." (P19, Male heterosexual, 43y)

"*It's really important to know what we are doing, but we don't know what we are doing. It is really horrific. Most people are like that. Amphetamine can destroy your life, but the point is we don't know. Most people think they are normal, including me. I thought I was normal, but actually, I wasn't. By using amphetamine, I would think how wonderful it was to use it. Then I rationalised my behaviour.*" [Later in the interview, he stated] "*This thing had made me being abnormal. In the past, I could control very well and take the medications regularly. After heavily using it over the past three months, I was changed and became abnormal. My use of medications became erratic, either. As you can see, I haven't refilled the medications for a month*." (P12, MSM, 35y)

According to P19 and P12's accounts, it was revealed that the psychoactive drugs they used could affect their cognitions, rationalise their drug-taking behaviour, and undermining their self-awareness. However, the degree to which illicit drugs impacted participants' cognition and HAART taking appeared to depend on their self-control over their drug-using and HAART-taking behaviours, which is discussed in **Chapter 8: Conscious actions**. Drawing on P19 and P12's data, it shows that the low levels of values placed on HAART taking was influenced by the addictive effects of drugs on their cognition and emotion response to external difficulties. P12, for example, started to heavily use amphetamine after breaking up with his ex-partner. His heavy use of drugs helped him to focus on his work and avoid difficult emotions (**Section 6.2.1.2.2.**). His emotional state and heavy use of drugs undermined his cognitive functioning and ability to control his HAART- and drug-taking behaviour.

To sum up, it seems that participants prioritised what was important to them based on their beliefs and preferences. When valuing illicit drugs more than HAART, some were inclined to use drugs and intentionally ignored dosing

times. On the other hand, the impact of illicit drug use on participants' cognition and emotion also influenced their values placed on HAART and control over drug-taking bad HAART-taking behaviour.

7.2.2. Developing the values of taking HAART

Exerting conscious control to override drug-taking behaviour and embrace regular HAART use was difficult and challenging for some participants. It required their considerable cognitive resources and valuing HAART. The value participants placed on HAART was revealed to increase their motivation to initiate and/or maintain HAART-taking behaviour. To better understand the mechanism of developing the value of HAART taking, three subcategories emerged within analysis— perceived benefits of HAART and perceived severity of erratic HAART use, having life aspirations, and developing the values of taking HAART.

7.2.2.1. Perceived benefits of HAART taking and perceived severity of erratic HAART use

In **Section 7.2.1.1.**, it has been discussed that some participants tended to hold negative assumptions of HAART, and this influenced their perception of HAART and subsequent HAART taking. On the other hand, within the data, it was revealed that some participants developed the values of HAART taking through their perceived benefits of HAART taking and the perceived severity of erratic HAART use. In addition, personal experiences emerged in the analysis to reinforce these perceptions.

> "*HAART can increase my CD4, boost my immune system, and make my viral load undetectable. This is a big motivator for me.*" (P2, MSM, 32y)

> "*Why I take the medications is that I want to live longer and protect others against HIV transmission. This makes me want to continue my treatment*." (P12, MSM, 35y)

"*It is better to not stop the treatment because it could cause drug resistance. If it happened, there won't be any treatment available for me*. " (P4, MSM, 26y)

Participants' perception of regular HAART use and its impact on personal and partner's health resonates with "perceived benefits" and "perceived severity" in the HBM (Becker, 1974, Janz and Becker, 1984, Rosenstock, 1974a and b), (**Chapter 3**). These concepts all convey how an individual's acknowledgement of the benefits and risks of a health condition/treatment can influence his/her beliefs and motivation. The examples from P2, P12 and P4 illustrated that their acknowledgement of the benefits of taking HAART and the risks of erratic HAART use enabled them to see its importance. Of particular concern, it was evidenced that some participants were more aware of the importance of regular HAART use when perceiving the severity of erratic HAART use. With its risks in mind, participants were more inclined to be cautious about their HAART taking.

"*During the time I engaged in a lot of risky sex, I knew I should regularly take the medications. I also cared about my diet and tried to eat healthily. In the meanwhile, I kept engaging in drugs and sex. I couldn't stop. I knew I shouldn't indulge in it. But I couldn't stay away from it. I knew I wasn't in a good condition at that time. Hence, I was particularly aware and thus took the antiretroviral medications regularly.*" (P3, MSM, 37y)

"*As long as they are medications, they are always more harmful than beneficial. To me, the benefit of the treatment I can think of is only the decrease in viral load.* [I probed further that it seemed that you consider it is more harmful than beneficial. What motivates you to regularly take the medications? And he answered] "*I have taken the medications. I won't stop because I am afraid that it might develop drug resistance. If anything happens, there won't be medications available for me.*" (P4, MSM, 26y)

"*At the beginning of the treatment, I was particularly cautious, because I wanted to get better. Even when I was injecting drugs, I would remind myself to take the medications.*" (P15, Male heterosexual, 53y)

The examples presented above showed that P3, P4, P15's heightened level of awareness regarding the importance of regular HAART use was due to their perceived severity of erratic HAART use, and its impact on their health. In the case of P4, although he perceived HAART as more harmful than beneficial, he still regularly took HAART due to his concern over drug resistance. His perception of the potential risk and loss appeared to particularly raise his awareness regarding the importance of regular HAART use. In line with P4, P1's statements presented in **Section 6.2.1.2.**— "*This is humanity... If I know this is the last chance, I wouldn't have missed doses*", also illustrated that he placed low levels of values on HAART due to his lack of awareness and concern about the importance of regular HAART use. The findings are in line with the PMT (**Section 3.4.1.4.**). In this theory, it is proposed that one's perceived threats could increase the probability of selecting adaptive responses (Rogers, 1975, Weinstein, 1993). When perceiving the threats brought by an object, an individual is more inclined to raise the awareness. On the whole, an increase in awareness with regards the necessity of regular HAART use seemed to help enhance personal values placed on HAART and increase motivation in regularly taking HAART.

From a temporal perspective, P3 and P15's narratives showed that they tended to regularly take HAART at the early stage of HAART, whereas once their viral load was stabilised, their perceived need for regular HAART use was diminished (**Section 7.2.1.2**.). The findings indicated that the value participants placed on HAART and its long-term management may not always stay the same but tend to be dynamic. Congruently, values are viewed by Rokeach (1973) as not completely stable. Instead, value priorities can be rearranged as a result of personal experience, society or culture (Rokeach, 1973). P14 and P20's narratives shown below pointed to the notion that the value they placed on HAART varied in intensity, which can be

extended to personal experience and/or health professionals' delivery of education.

Examples of developing values through personal experience with HAART use:

> "*I don't know how come they can live that long without taking the treatment. To me, though I was almost influenced by them, I prefer to believe what doctors have told me as to the lab data. You can see that there is a big difference in viral load between the time I didn't take the treatment and the time I take the treatment now. It means that my health is improving. This is the key motivator for me. To me, now I believe the treatment.*" [At the end of the interview, he added that] "*Firstly we need to be willing to take the medications, and then we will be more likely to regularly take HAART. The key is our internal part. We should be willing to take it first.*" (P14, MSM, 36y)
>
> "*At the beginning, I was afraid. I didn't know if this treatment would affect me a lot. Then I asked my friend who is HIV positive. I asked this friend if I should take the treatment. He said I didn't need to worry and it would be fine. Now I am receiving the treatment. I feel nothing.*" [Later in the interview, she added] "*Every three months we have to go for a check-up of viral load and CD4. Every time I could see how much they have been improved. My health is getting better. I could feel that this treatment is effective. Then I know I can take the treatment.*" (P20, female heterosexual, 36y)

Examples of developing values through health professionals' delivery of education on HAART:

> "*The HIV specialist told me a very important concept of the treatment, which is why we need to take the medications and how it minimises the chance of transmitting the virus to others. Then, I realised how important it is.*" (P12, MSM, 35y)

> "*I called the HIV specialist to discuss my experience of side effects of the treatment, and she said it is normal and the side effects should alleviate within few days. Then really, those side effects were gone after few days. And now I am quite used to this regimen*." (P19, Male heterosexual, 43y)

The values that 14 and P20 placed on HAART changed as they learnt and experienced. Their positive experience of HAART use and optimal treatment outcomes strengthened their beliefs and values relating to HAART. In the cases of P12 and P19, at the early stage of HAART trajectory, they appeared to lack the knowledge of HAART. Nonetheless, with health professionals' informational support, they developed a better understanding of their HAART regimens and came to value HAART and develop competence in tackling their regimens.

Taken together, participants' engagement with HAART taking were guided by how much they valued HAART. Such value creation mechanism appeared to involve individuals' perceived benefits of taking HAART and perceived severity of erratic HAART use and through their reflection of personal experience. As a result, it assisted some participants in learning, heightening their awareness, and informing and guiding their HAART-taking behaviour.

7.2.2.2. Having life aspirations

In **Chapter 6**, it was discussed that some participants' suicidality influenced their engagement with antiretroviral treatment. Their attempted suicide and suicidal thoughts were revealed to be due to their emotional distress and low levels of value placed on life with HIV. On the other hand, the data presented below showed that participants who valued life and had life aspirations enhanced their engagement with HAART taking. These participants alluded to the notion that the value they placed on life was linked to their feelings of being supported and subsequent development of meanings and purposes in life. In that sense, it seemed that how they valued HAART and their life aspiration were formed through the interaction between participants and the context where they lived.

"*What keeps me to regularly take medications is my sister. She always takes care of me and financially supports me. My parents also care for me. They let me live my life without worries. I want to be good. I want to do something for them. I have so many things that I want to do but have not done yet. I want to live. I want to do something for them*." (P16, Male heterosexual, 42y)

"*I take the medications because my thought has been changed. Nowadays HIV is not that horrible and also I have a son. I want to live longer and see him grow up and have his own family*." (P15, Male heterosexual, 53y)

"*I want to live. I don't want to let my family down*." (P11, MSM, 31y)

"*Basically, I can regularly take the medications because I want to live longer and I want to be with my family*." (P13, MSM, 31y)

Drawing on their narratives, it showed that support from the family had given participants hope and aspiration to live, thereby they valued HAART and felt motivated to regularly take the medications. In addition to external support resources, such value development also needed participants' internal validation, by which it means their deep-seated beliefs in the meaningfulness of regular HAART use brought to their life. By the same token, 'self-evaluation' and 'Forethought', discussed in social cognitive theory (**Section 3.4.2.2.**), provide similar notions of 'life aspirations' discussed here (Bandura, 1991 and 2001). In the theory, self-evaluation of personal standards and environmental circumstances, and an individual's thought about the present and foreseeable future were proposed to trigger motivation and change in behaviour. P6's and P8's extracts presented below illustrate their life experience was subjectively evaluated, and subsequently, meanings attached to HAART taking and motivation were developed.

"*Previously I volunteer in an association and I have seen people who are bed-ridden and cannot look after themselves. I am afraid. I don't want to be like that*." [Later in the interview he added] "*If I don't take the*

treatment I will die. I am afraid of death. I want to live. I want to live." (P6, MSM, 52y)

"*If I want to live, I need to regularly take the medications. Although it is a chronic disease, if I don't regularly take them I will get opportunistic infections. I have a friend who had treatment interruption for a while and also used drugs. He quickly developed opportunistic infections. I have another friend who can't walk anymore*." (P8, Male heterosexual, 49y)

The values that P6 and P8 placed on life with HIV and the necessity of regular HAART use enhanced their commitment to regular HAART use so as to live longer. Congruently, P12 and P7's narratives presented below illustrated that the values that they placed on HAART were aligned with their aspirations of what they wanted their life to be like. The excerpts— "*The reason why I am taking the medications is to prolong my life… I want to pursue my dreams*" and "*Why I need to live… HIV and cocktail treatment are the gifts from God*" conveyed not only their perceived importance of HAART taking but their aspirations in life.

"*The reason why I am taking the medications is to prolong my life and protect others. That's why I continue my treatment. Nowadays, we can live until 70-80 years old. I want to pursue my dreams, like promotion and increase in salary. This year my life will be different. I want to help others.*" (P12, MSM, 35y)

"*I have changed my thoughts and now stay in faith. I mean I modified my value. It is hard to modify my own value. I need my family's support and I also need to step into a different environment to feel and experience different things and to establish my value.* [I asked what the value is, and he answered]. *"The value is how to define my life. Why I need to live. This is the value attached to my life…To me, now HIV and cocktail treatment are the gifts from God. This treatment has pros and cons, but it depends on us as to how to view it and to use it*." (P7, MSM, 30y)

P12's narratives showed that his life aspirations enhanced valuing HAART and strengthening his will to take it. This implies that values attached to living with HIV and HAART can orient an individual's tendencies and actions. P7's narratives pointed to the notion that changing or modifying his values of life with HIV and HAART goes beyond regarding it as important. Rather, P7 was able to appreciate its qualities and invest effort on transition in thoughts and behaviours.

In short, with life aspirations, some participants appeared to be driven and more determined to create the life that they wanted to live. Their life aspirations were revealed to come from their connections with the social context and the values they placed on life. By valuing their life, participants were inclined to value HAART in an attempt to prolong life and pursue goals. In that sense, it seems that values are an expression of future orientation and life purpose. By having life aspirations and developing values of life with HIV and HAART, participants were more likely to feel motivated and to actively engage in taking HAART.

7.2.2.3. Developing the mindset of valuing HAART taking

In **Section 7.2.1.2**, P13's mention of *"心態"* was an expression of setting his mind by deeply valuing HAART and from the bottom of the heart. Without such mindset, P13 articulated that a person would not take action to actively manage antiretroviral treatment. However, during the trajectory of HIV and HAART, a number of participants appeared to be able to develop a mindset that facilitated their HAART-taking. When placing the value on HAART taking, participants appeared to perceive its importance, develop the mindset, and make regular HAART use a reality.

> "*Yes, I must take it. If my CD4 gets lower, I can develop some kinds of infectious diseases.*" [Later in the interview he added] "*Not taking the medications makes me feel like it isn't right. I feel like no I cannot miss doses*." (P5, Male heterosexual, 45y)

"*I thought I am still alive, so I cannot let my CD4 cell count being too low. It will make me get infections.*" (P22, Male heterosexual, 50y)

P5 and P22's narratives— "*Yes, I must take it*", "*I feel like no I cannot miss doses*", "*I cannot let my CD4 being too low*" demonstrated that they tell themselves what they should do or what they cannot do in prevention of decreased CD4 cell count and opportunistic infections. It indicated that they perceived the importance of HAART. The words, 'must' and 'cannot' stated by P5 and P22 were in a strong sense that they set their mind on taking HAART. By setting their mind on taking HAART, it increased their motivation and their effort to take the actions. It is exemplified by P13 and P18's narratives.

"*I regularly take the medications, because I want to be in a healthy condition. I want to live longer and be with my family*." (P13, MSM, 31y)

"*It depends on self. If you want to persist in regularly taking the medications, you will."* (P18, Female heterosexual, 32y)

P13's and P18's mention of '*I want to'*, '*persist*' and '*will*' illustrates that driving force and strong mindset guided and influenced their HAART taking. In the example of P13, because he wanted to live longer, he made it happen by regularly taking HAART. Taking this into account, it seemed that valuing life with HIV and HAART plays a big role in conditioning participants' mind to engage with HAART, as if it was values that governed their thoughts and motivated their behaviour. Congruent with this notion, P7's narratives below showed that he developed a mindset in favour of regular HAART use by focusing on and valuing the good sides of HAART. With positive thoughts about HAART, his mind seemed to go towards that way, contributing to regularly taking HAART.

"*Finding its positive side and looking at its positive side. Also, it is needed to know its negative side, but we shouldn't be overly concerned and address that part. Instead, we should always think about its good*

bits. As long as I have this kind of mindset, it is more than enough to help me regularly take the medications." (P7, MSM, 30y)

"*My attitude is that I don't feel like I like the medications, but I would view it as part of something that I have to do. Just regularly take it*." (P13, MSM, 31y)

In the case of P13, he did not like HAART, whereas he perceived the importance of taking HAART so as to live longer and be with his family. His negative feelings towards HAART and perceived importance of taking HAART appeared to coexist. By focusing on what he wanted to do and had to do in mind, it seemed to have enabled him to let his rational mind prevail over his negative feelings towards HAART. As such, it indicates that the presence of negative emotion does not imply the absence of embedded rational thought. Rather, it was mainly his thinking which led towards developing values and a mindset that could facilitate regular HAART use. Meanwhile, he also accepted his feeling/emotion towards HIV and HAART.

Findings presented so far showed that participants' thoughts and emotion were inextricably bound together. In line with P13, P19 and P14's narratives presented below also illustrated that developing the mindset of valuing life with HIV and HAART brought their intelligence and rational thinking to bear upon emotion.

"*By perceiving what kind of life you want to live, it would affect how you view everything. My mindset would affect how I see everything*. *Some people might give up themselves and stuff like that. Some might be more optimistic and not view HIV negatively. It's the way you view things.*" [Later in the interview, he stated] "*When I have the right mindset, I won't be affected by other people*." (P19, Male heterosexual, 43y))

"*Whether or not to regularly take HAART depends on our deep belief in HAART and our value of our own life*." [Later in the interview he added] "*People who are willing to accept self and the treatment are less likely*

to be affected by drugs. I should say that our internal part is the key." (P14, MSM, 36y)

In summary, having the mindset was revealed to play an important role in activating participants' desire and motivation for regularly taking HAART. With such a mindset, it guided participants to perceive the world in a certain way and act upon. In reverse, the way participants perceived HIV and HAART through their experience also changed the priority of the values they placed on HAART and subsequent HAART-taking actions (**Section 7.2.2.1.**). Similar to the notion identified from the data, Rokeach (1973) views 'value' as relatively stable over time. It is stable enough to reflect the sameness and continuity of an individual's personality within a given social context. Yet, it is also unstable enough to permit the re-organisation of value priority.

7.3. Discussion

The concept of health values can be applied in a similar manner as the concept of beliefs elucidated in the HBM. Both refer to the degree to which an individual has the trust or faith in health, treatment or behaviour (Becker, 1974, Janz and Becker, 1984, Rokeach, 1973, Rosenstock, 1974b). In the HBM, it was felt that perceived benefits, perceived barriers, perceived susceptibility, and perceived severity were proposed to provide sufficient motivation to perform health behaviour. Nonetheless, it seems to somewhat confuse expectancy with motivation, and did not give sufficient explanation of the linkage between the two. Becker and his associates (1972) re-evaluated the model, and pointed out that an individual's feelings and concerns are important components of his/her motives. Accordingly, they further suggested that the four dimensions of the HBM could predict health behaviour but only among those who highly value health (Becker et al., 1972). One of the limitations of their study is that the concept of values was not clearly defined. Compared with beliefs, the concept of values provides a deeper sense of an individual's beliefs that can drive subsequent behaviour (Rokeach, 1973). Nevertheless, one major theoretical issue is that though values have been

proposed as an important concept of illustrating health behaviour; however, values have not been extensively explored and are difficult to be directly measured (Lau et al., 1986, Rokeach, 1973).

'Attitudes' is another term that has been compared with 'values' in Rokeach's (1973) book. In his book, he maintained that 'values' is a dynamic concept, having a more immediate link to motivation. Compared with 'values', 'attitudes' is relatively peripheral in the belief system and is viewed as a casual belief about an object or situation. Fundamentally, 'attitudes' is the function of 'value' (Grube et al., 1994, Homer and Kahle, 1988). When choosing a term that can represent the data, 'values' was chosen because of its more central position.

In this study, values appeared to play a central role in participants' HAART-taking behaviour, and could drive their underlying motives for HAART-taking behaviour. To understand HIV-positive drug users' HAART-taking, it is important to gain insight into the values they place on HAART. At the beginning of HIV trajectory, some participants tended to possess negative emotions towards HIV and HAART and lack the knowledge of HAART. Their lack of knowledge was apparent mainly in relation to their unfamiliarity with HAART and preconceptions of HAART. Without effective communication with health professionals, they could even form a block in the channel of acquiring accurate information and clarification. In turn, what they believed to be true and good for them had further negatively influenced the value they placed on HAART and directed their disengagement with HAART taking. With adequate knowledge, it does not necessarily increase the levels of valuing HAART. To shape an individual's values, it was evident in this study that personal preference and tendency can determine value priority. Some participants tended to value drugs more than HAART; others tended to not perceive the importance/need of taking HAART regularly. Together, these led to participants not perceiving regular HAART use as important or necessary.

On the other hand, this study showed that individuals' development of values attached to HAART involves their emotional stability and weighing potential

risks and benefits of regularly taking HAART. The values they placed on HAART were arrived at through careful thoughts and reflection on the experience of taking HAART. By developing the values of regularly taking HAART, participants were more inclined to feel interested and motivated in investing time and efforts for it. In addition, the data demonstrate that to value HAART goes beyond regarding it as important; instead, it requires a person to develop the mindset of valuing HAART and keep it front and center, be oriented towards future, and be willing to make time and/or effort for it. Life aspirations was revealed to be aligned with the values attached to HAART. As participants had life aspirations for future events and connected with people and the environment, they were more likely to value HAART taking and strengthen their will to actively engage in it. In that sense, values can be an expression of future orientation and life purpose. However, it should be bear in mind that the values participants placed on regular HAART use were relatively stable but did not always stay the same. Rather, this study demonstrates that a value could change in its intensity and order over time as a result of the change in personal experience, social context, and culture.

Taken together, ‘values’, therefore, refers to what an individual believes to be important at a deep level here. In other words, the values an individual holds seems to be a reflection of what she/he deeply and desirably believes and feels. It is the deep-seated belief that is targeted towards an individual’s needs and motives for behaviour.

CHAPTER EIGHT: CONSCIOUS ACTIONS

8.1. Introduction

In the last chapter, it was evident that values are an important driver of participants' HAART-taking behaviour. In other words, by placing a value on HAART, it seemed to act as a driving force to direct participants' HAART-taking behaviour. However, to strictly follow a prescribed HAART regimen throughout the treatment process, data revealed that participants would need to make a conscious effort and be mindful of their HAART taking in the present moment and under the given situations. Therefore, this chapter focuses on participants' conscious awareness and implementation of conscious actions, and how it impacted their regular HAART use.

This chapter is divided into two main sections. The first section looks at participants' experiences of taking HAART without conscious engagement at the correct time and in a given situation. The second section focuses on participants' experiences of consciously managing regular HAART use through their self-control and self-adaptation. The elements of the two main categories were summarised and presented in **Table 9**.

Table 9: Constructs of conscious actions

Concept	Category	Sub-category
8.2. Conscious actions	8.2.1. Not taking conscious actions on HAART taking	8.2.1.1. Lack of conscious awareness of HAART taking
		8.2.1.2. Not incorporating HAART into everyday life
	8.2.2. Taking conscious actions on HAART taking	8.2.2.1. Self-control over HAART-taking and drug-taking behaviours
		8.2.2.2. Self-adaptation 8.2.2.2.1. Self-protection 8.2.2.2.2. Use of external stimuli

8.2 Conscious actions

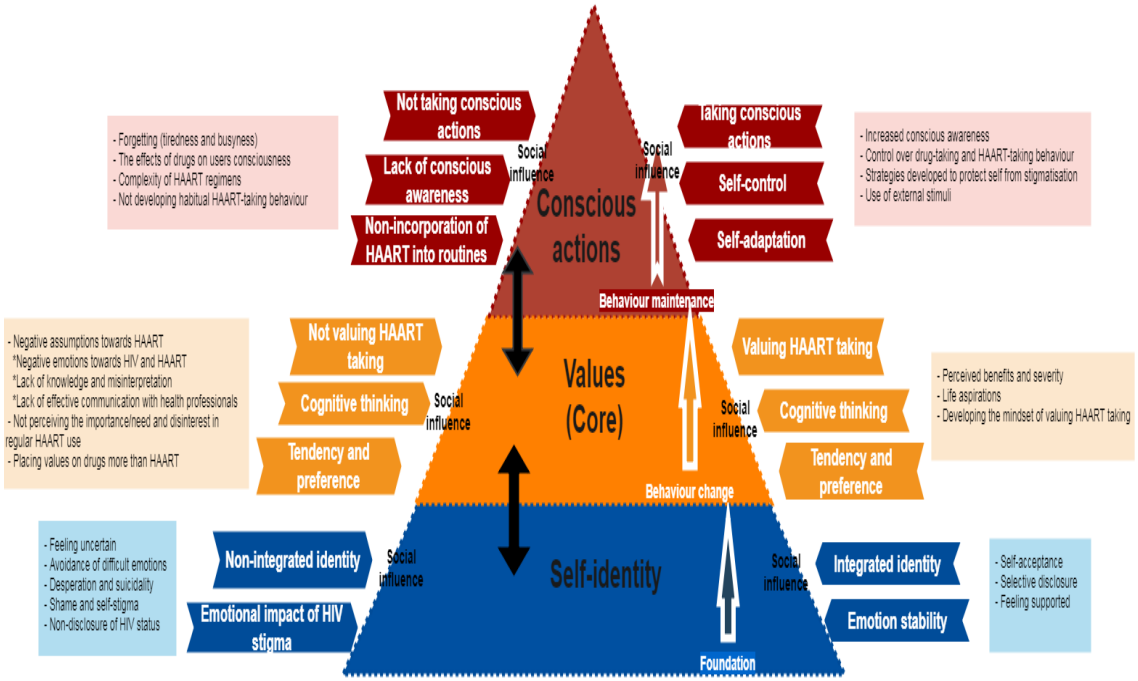


Figure 11: Identity-Values-Conscious Actions Model for sustaining HAART-taking behaviour

Figure 11 shows that individuals'' integration of HIV-positive identity into sense of self is fundamental to self-acceptance and emotional stability. The values individuals placed on HAART taking can drive their HAART-taking behaviour. Conscious actions emerged from the analysis as the key concept

that could greatly influence participants' ability to sustain their regular HAART use. "Conscious actions", here, is referred to as an individual's ability to be aware of and attend to HAART taking in the present moment and the demands of any given situations. The cocnept, conscious actions, is divided into two parts, 1) not taking conscious actions on HAART taking and 2) taking conscious actions on HAART taking, to explore its impact on participants' ability to sustain regular HAART use.

8.2.1. Not taking conscious actions on HAART taking

Drawing on participants' narratives, most of the participants had the experiences of forgetting to take HAART regimens during their treatment process. Participants' forgetfulness was found to be linked to whether they consciously managed their HAART taking at dosing times and in a given situation. Under this category, there were two facets that emerged from the data to influence participants' HAART-taking behaviour— lack of conscious awareness of HAART taking, and not incorporating HAART into everyday life.

8.2.1.1. Lack of conscious awareness of HAART taking

As discussed in **Chapter 7**, participants with a lack of value placed on HAART were less likely to invest time and efforts on HAART taking, which contributed to mindlessly managing their HAART taking. In this case, they tended to intentionally miss doses. On the other hand, even when participants tended to place values on HAART taking, many of them had unintentionally forgotten doses sometimes. It was evident in the data that their unintentional forgetfulness on medication taking was due to their lack of conscious awareness.

> "*When I watched movies, I didn't notice my pill box, and the dosing time passed. When you looked at your pill box, you would know if you have taken your medications. If you didn't notice it, you would forget. The next day, when I opened my pill box, I found out that I hasn't taken my dose yesterday*." (P6, MSM, 52y)

"*He wouldn't remember whether he has taken doses or not. He skipped a dose because he didn't know if he has taken doses. He took a double dose because he thought he hasn't taken yet but actually he has*." (P13, MSM, 31y)

P6 and P13's narratives —'*if you didn't notice it, you would forget*', '*wouldn't remember*' and '*didn't know if he has taken doses*' demonstrated their unawareness of the dosing times. Without consciously engaging in their HAART taking, participants were less able to attend to HAART taking, and to exercise control over HAART-taking behaviour, leading to intentionally missing doses. In the case of P6, his narratives, presented in the **Section 7.2.1.2.,** pointed that he rarely missed doses, less than 3 times a month. He still sometimes missed doses during the treatment process. Echoing the findings, Bandura (2001) in his social cognitive theory from an agency perspective illustrated that an individual's consciousness is a very important element in his/her mental life, which can make life more manageable. This implies the central role consciousness plays in the cognitive regulation of action.

Many participants' lack of conscious awareness of HAART taking surfaced mainly in relation to their tiredness and busyness.

"*I did not take it mainly because I was busy. If I was busy, I would forget. Too many things to do.*" (P3, MSM, 37y)

"*I was too busy at work. I forgot. I was too tired and I fell asleep. In that situation, I would forget to take doses*." (P7, MSM, 30y)

"*When I got back in the evening, I was tired. In other words, after taking a shower, I would want to sleep right away and then I forgot your doses. This incidence is rare, less than one time every 2-3 months*." (P8, Male heterosexual, 49y)

"*When I was tired after work, I would want to sleep. I wouldn't remember taking medications. I would notice it the next day, thinking that OMG I forgot taking medications*." (P9, MSM, 35y)

P3, P7, P9's mention of 'too many things' and 'busy at work' illustrates that their involvement in other activities shifted their focus onto matters of concern other than HAART regimens. By taking participants' attention away from their dosing times, it increased their likelihood of missing doses. In addition, drawing on P7, P8 and P9's narratives, their busyness from work also increased their feeling of exhaustion. The narrative — '*would want to sleep right away*' was in a sense that they could not process any more information but shut off their brain. With such feelings of exhaustion, participants appeared to decrease their awareness and attention on dosing schedules.

In the case of participants who were on drugs, concern over the effect of drugs on impairing an individual's ability to mindfully manage HAART taking has been brought up by many participants. Some examples are presented below.

"*Using drugs would impair your hypothalamus. Sometimes, I thought I have taken medications. As I checked all of my medication afterwards, I found that I still had many medications*." (P4, MSM, 26y)

"*Amphetamine can really impair my memory. To me, now I needed to take note so that I would be able to remember to take medications. After I took drugs, I would just stare at the screen of my computer. Even not blinked my eye. So I would forget and ignore something else. I completely ignored other external stimuli.*" (P12, MSM, 35y)

"*When using amphetamine, I would be alert and fixated on my things. I wouldn't take medications.*" (P15, Male heterosexual, 53y)

"*Basically if you used drugs, your memory would get poorer. If you forgot, then you wouldn't take it regularly. The regularity would be affected. One time, I forgot if I have taken the medications. The other*

time, I have taken the medications, but I forgot I have taken and took them again." (P13, MSM, 31y)

Drawing on the data above, when on psychoactive drugs, it changed participants' state of consciousness and/or impaired their memory. Without cognitively engaging in HAART taking, some had difficulty in remembering whether they had taken medications or not. As such, it indicates that external influences can undermine individuals' consciousness and impede HAART-taking behaviour. Nonetheless, in the existing theoretical literature, notions in relation to how and in what situation an individual's consciousness cannot be well involved in health behaviour have not been deeply explored. Such unsatisfactory expositions of consciousness were found to be due to the emphasis scholars placed more on functional aspects of consciousness in health behaviour (**Chapter 3**) rather than its phenomenal aspects (Bandura, 2001).

In short, participants' unawareness of HAART taking were more likely to occur when they were not in that state of mind of taking it during dosing times and in a given situation. Commenting on this, most participants who were not on drugs were unanimous in the view that their unintentional forgetfulness was commonly caused by external stressors, such as busyness and subsequent feelings of tiredness. Under the situation of using drugs, some alluded to the notion of the effects of drugs on altering their consciousness and impairing their memory. Considering these accounts, feeling busy or tired and under the influence of drugs seem to take participants' attention and energy away from HAART taking. By not 'being there' to notice dosing times, it can increase the likelihood of missing doses, leading to inconsistency in following prescribed treatment regimens.

8.2.1.2. Not incorporating HAART into everyday life

Without establishing a lifestyle that incorporated HAART into routines, participants, on the whole, demonstrated that the level of their conscious engagement with HAART taking was lowered. Consequently, this contributed to missing dosing times. Two common issues were identified from

participants' experiences where they could not or did not integrate dosing schedules into their daily routines — the complexity of HAART regimens and not developing habitual HAART-taking behaviour.

> "*I feel thankful that the medication regimens are more simplified nowadays. In the past, I needed to take medications twice a day. And this caused me to forget doses sometimes. Because the regimen was more complicated. Two pills in the morning, three pills in the evening. I needed to organise pills by myself…Now I just need to take it once a day. At 8 am every morning. Taking it once a day is less likely to cause me to forget. Previously I forgot taking medications not because I didn't take the medications but because I couldn't remember I had taken 2 pills or 3 pills.*" (P20, Female heterosexual, 36y)

> "*My previous regimen was taken twice a day. Different types of medications were taken at different times. When you didn't want to let others know what you were taking, taking medications with you and on time was challenging...My current regimen is more simplified* [In his socio-demographic information, it showed that he is currently taking one pill before sleep per day. The last time he missed doses was one year ago when he still used a more complex regimen]*. In the past, I needed to take 4-5 pills at one time. It was suffering.*" [Later in the interview, he added] "*I changed to this regimen, because I often missed doses. Time issues*." (P9, MSM, 35y)

> "*Firstly, the white pills needed to be put in the fridge. That was so inconvenient. Secondly, I needed to take so many cocktail medications in the early era. Now I don't need to*." (P12, MSM, 35y)

Based on P20, P12, P9's narratives, it showed that HAART regimens in the past were more complex in comparison to current treatment regimens. The simplicity of HAART has decreased the amount of time and efforts that P20, P13, P9 needed to invest for regularly taking HAART. As a result, it helped participants to incorporate their regimens into daily schedules and decreased

the likelihood of forgetting or missing doses. In the case of P9, his self-stigma along with the complexity of his regimen collectively impeded his HAART-taking behaviour. However, since he changed the regimen to a more simplified one, it helped him to manage his HAART more easily and mindfully. Congruently, the empirical evidence discussed in **Chapter 4** also showed that the change in the HAART regimens over the period between early HAART era and recent HAART era has enhanced users' adherence (de la Hera et al., 2011, McNeil et al., 2017, Mimiaga et al., 2010, Wittveen and Ameijden, 2002).

There were participants who were able to incorporate HAART into routines and developed habitual HAART-taking behaviour. However, data revealed that such habitual and routinised acts did not necessarily involve consciousness. When taking HAART medications in a new or changing context, this requires the person to more consciously engage with HAART taking at the correct time. The data presented below showed that due to a lack of conscious engagement with HAART taking in the changing environment events, some were not able to manage to bring medications with them contingently, leading to missing doses.

> "*If I am on a business trip for 1or 2 nights, I would sometimes forget to take the medications with me. If I remember I would bring them. If I forgot, I would take it next day*." [Earlier in the interview, he stated his habitual HAART use] "*Taking medications has become a habit for me now*." (P19, Male heterosexual, 43y)

> "*When I went out, I forgot to take medications with me. Sometimes, I visited my mum and stayed with her for one or two days, and then I forgot to bring my medications. Actually, I had prepared, but just forgot to bring my medication bag*." [Earlier in the interview, he mentioned about his habitual HAART use] "*It seems like a habit of taking the medications to me now*." (P5, Male heterosexual, 45y)

> "*One time I went for a trip, I forgot to bring my medications. My wife was really upset that I forgot to bring medications*." [Earlier in the interview, he stated his habitual HAART use] "*Taking the medications has been set into my biological clock now*." (P8, Male heterosexual, 49y)

According to P19, P5, and P8's socio-demographic information, it showed that they followed prescribed medications most of the time. Nonetheless, they seemed to be trapped in a rigid perspective of their usual way of taking HAART. Without being conscious of their HAART-taking act and linking the act with different environment events, it led to forgetfulness.

This notion resonates with "self-reactiveness" in social cognitive theory by Bandura (1991 and 2001). Self-reactiveness places an emphasis on an individual's deliberative ability to give shape to appropriate courses of action and regulate the execution (Bandura, 1991 and 2001). In this study, without consciously engaging with HAART taking at dosing times and in a given situation, participants tended to perform the behaviour devoid of subjectivity and conscious control.

In summary, to sustain consistency of regular HAART use required participants' conscious engagement with such acts at the correct time and in a given situation. However, it seems challenging to maintain a high level of consciousness throughout the HAART trajectory, both at the beginning (those who have not incorporated HAART into everyday life) and at the maintenance phase (those who have established habitual HAART-taking behaviour). In that sense, it implies that the operation of conscious engagement with HAART taking does not exist in isolation from the external environment; rather it required participants to be aware of external influences, and proactively and consciously manage their HAART-taking in the demands of given contexts.

8.2.2. Taking conscious actions on HAART taking

In this study, consciousness is construed as a controlled and intentional process where one could reflect upon mental activity and foster self-control

and self-adaptation so as to fit HAART use into external environment and different situations. In that sense, with consciousness, this allowed participants to manage the long-term treatment more intentionally and strategically. In the following, taking conscious actions on HAART taking involves self-control over the behaviour and self-adaptation.

8.2.2.1. Self-control over HAART-taking and drug-taking behaviours

Section 8.2.1. discussed that a lack of conscious engagement can undermine an individual's management of HAART taking. On the other hand, exerting self-control was revealed to increase the likelihood of maintaining participants' regular HAART use in this study. When participants had the control over their behaviour, external influences and use of drugs were less likely to impede their regular use of HAART. It is exemplified by P1's and P9's experiences.

> "*My viral load was undetectable once before. My viral load went undetectable during the period between June and December 2014. At that time, I had a stable job, working from morning to evening. After work, I felt tired. I was very healthy at that time. Basically, there were many temptations, but I wouldn't want to go out and have chemsex. The reason I didn't engage in it was my controllability. When I wanted to have fun, I would go for it. When I wanted to stop, I would stop*." (P1, MSM, 28y)

> "*Using drugs wouldn't affect my regular use of medications, as long as I didn't overly engage in chemsex. As I mentioned earlier, you should know how to engage in chemsex and how to control self to not be influenced by drugs. So I think it doesn't matter*." (P9, MSM, 35y)

Although P1 did not regularly follow prescribed HAART regimen at the time of interviewing, he had regularly taken a HAART regimen before. His regular HAART use was established when he had a healthy lifestyle and did not engage in chemsex. By his definition, a healthy lifestyle seemed to mean having a stable life and not engaging in chemsex. His expressions— "*When I*

wanted to…, I would.." and "*It was my controllability*", illustrated the notion that his decision on whether or not to take HAART and to engage in chemsex depended on what he wanted and valued and his self-control. The words 'wanted' and 'would' used by P1 were in a sense that he placed values on HAART taking (**Section 7.2.2.**), which subsequently drove his HAART-taking behaviour and strengthened his willpower to control his behaviour. P9's account —"*you should know how to…and how to control*" — implicitly indicates that through the process of his cognitive evaluation, he was able to control his own behaviour. In that sense, it seems that an individual's values and self-control are inextricably linked. In the same vein, self-efficacy in the HBM, self-reflectiveness in social-cognitive theory, and perceived behaviour control in the theory of planned behaviour all convey the belief in an individual's ability to perform and control behaviour (Ajzen, 1985, 1991 and 2002, Bandura, 1991 and 2001, Rosenstock et al., 1988). Accordingly, participants' deep belief in the importance of regular HAART use had enhanced their perceived and actual behaviour control through self-evaluation and self-reflectiveness.

P9's mention of not overly engaging in chemsex so as to regularly take HAART indicated his ability to inhibit and resist interference from overuse of drugs. In **Section 7.2.1.3.** and **8.2.1.1**., participants' narratives revealed that drugs could exert a significant and negative impact on their medication taking. One of the main challenges faced by drug-using participants to regularly take HAART regimen was their craving for the euphoric effects of drugs and withdrawal symptoms. Such feelings were discussed in **Section 7.2.1.3**. to draw some participants' attention away from receiving HAART and to decrease the value they placed on HAART. Nevertheless, by taking control from overly indulging in drugs, it helped current drug-using participants to consciously manage their HAART taking. The examples are presented below.

> "*There were some who used drugs and at the same time regularly took medications, if not craving for the drowsiness [drug effects]. I mean not*

injecting heroin heavily to fall asleep. It would be enough to just use heroin for avoiding withdrawal and not let myself feel too discomfort." (P18, Female heterosexual, 32y)

"*Now drugs don't affect my use of medications. I have my own rules. I used amphetamine only when I was in a good mood. Because if you use it when you feel down, it will make your emotion even worse*." (P21, MSM, 35y)

P18 and P21's narratives presented above showed that they were able to temper what they wanted and to ensure that they were not over indulging. By developing the mindset of valuing HAART, it helped them to be more conscious of and exert control over their behaviour. In addition, an individual's self-control involves not only the values he/she places on HAART but also perseverance. ,

"*I told myself. I have to take the pills. It becomes like a habit. Also, I usually take medications with me. I know I must take the medications. I always tell myself I must take medications and I cannot miss doses. I have to think that if this regimen is not effective I will need to change to another regimen*." (P10, Female heterosexual, 33y)

"*I am a careful person. Regardless of whether I use drugs or not, I would be careful about my medication taking. Since I started the medications, I forgot taking pills only less than 10 times. Maybe even less than 5 times. Because I always remember that there are limited regimens available. If I run out of the regimens, I can only wait for death*." (P11, MSM, 31y)

In the examples of P10 and P11, the sociodemographic information (**Appendix 1**) showed that P10 never missed doses, and the last time P11 missed doses was more than 3 months ago. The words — 'must', 'regardless of (situations)', and 'always remember' conveyed P10 and P11's determination and perseverance of regularly taking HAART in the demands of any situations. In particular, their high levels of conscious awareness on

the consequences of erratic HAART use played an important role in the development of their strong sense of perseverance and self-control.

By and large, participants in this study needed to manage not only HAART but also addiction. **Chapter 6** discusses drug use as a common coping strategy to avoid realities and difficult emotion among participants; **Chapter 7** discusses how heavy use of drugs could influence participants' cognitive thinking and decrease the values they placed on HAART; **Section 8.2.1.1.** looks at how drug use negatively impacted participants' consciousness and memory. These point to the notion that drugs posed a negative and significant impact on participants' medication taking. In an attempt to minimise the impact of drugs on HAART taking, some participants were able to control their drug intake, and this helped them to manage their regular use of HAART more easily and effectively. However, the key to self-control among participants was to value HAART first, and then they were more likely to be aware and persist on following prescribed HAART regimens.

8.2.2.2. Self-adaptation

Data revealed that the ways participants consciously managed HAART taking are closely linked with self-adaptation. Self-adaptation here is referred to as one's ability to apply cognition and reason to develop skills and adjust behaviour to meet goals. In this study, many participants demonstrated that they could adapt to changes in any given situations in an attempt to regularly take HAART.

As noted in **Section 8.2.1.2.**, a new and altering context increased the likelihood of participants' unintentional forgetfulness, negatively influencing their engagement with HAART taking. Such forgetfulness was particularly found to be due to their lack of attention and conscious awareness. While participants in this study differ in capabilities of allocating attentional resources to respond to contingencies in the environment, it was evident that some participants who placed values on HAART taking and persevered with regular HAART use were more likely to adapt to changes and difficult situations.

"*Thinking that if drug resistance occurs I will need to change my regimen and re-adapt to a new regimen. I want to avoid it, so I am quite careful about it*. *No matter how the medications could affect me, I would still take them*." (P13, MSM, 31y)

"*I always follow the prescribed regimen. The nurse told me that if I don't regularly take the pills, those will be ineffective. Then I will feel awful. Thus, even if I used drugs, I rarely forgot to take the pills*." (P11, MSM, 31y)

P13's account showed that his intention and purpose of regularly taking HAART provided direction for such acts. In line with P13, P11's account — "*Even if I used drugs, I rarely forgot to take the pills*" —offers an important insight into how the values he placed on HAART functioned as a point of reference for exerting conscious control over HAART taking, and self-adapting for accommodating his treatment schedule. As discussed earlier in **Section 7.2.2.2.**, the values P13 and P11 placed on HAART appeared to be established through their positive interactions with family. With the feeling of being supported by family and development of value of HAART, it fostered their directedness and enhanced their adaptability for managing HAART taking, regardless of the challenges they faced while taking HAART. Congruent with the findings, Bandura (1991 and 2001) in his social cognitive theory maintained that people do not have direct control over social conditions. However, the outcomes that individuals values can drive their motivation and mobilise their efforts to reach the attainment (Bandura, 1991 and 2001). When having shared values and beliefs with others, it can even lead to collective power to produce desired outcomes (Bandura, 1991 and 2001). To maintain proficiency under ever-changing conditions of life, Bandura (2001) suggested a continued investment of time, efforts, and resources.

In line with Bandura's notions, participants in this study appeared to develop skills and strategies, and mobilise resources in an attempt to maintain their regular HAART use. The narratives shown below illustrated the strategies

they developed to change or fit different tasks and environment features. Two aspects of participants' management of HAART taking are listed as follows: 1) self-protection to avoid stigmatisation and side effects of HAART and 2) the use of external stimuli to reinforcing HAART-taking behaviour.

8.2.2.2.1. Self-protection

In prevention of public stigmatisation, P10, P16 and P19's accounts showed that they were able to adopt an alternative explanation of HAART medications.

> "*In the past, I would say it was vitamins. Now my friend gave me an empty bottle. I would lie that I was taking supplements*." (P10, Female heterosexual, 33y)
>
> "*I would just tell them it was for my gout*." (P16, Male heterosexual, 42y)
>
> "*Last time I went abroad, my friend asked me what I was taking. I told them that it was vitamins. They believed it. We just wanted to protect ourselves. It was my privacy*." (P19, Male heterosexual, 43y)

In **Chapter 6**, HIV-related stigma was identified to be one of the major concerns amongst participants. The examples from P10, P16, and P19 demonstrated that by giving an alternative explanation of the medications taken, they were able to regularly take HAART while avoiding stigmatisation. In P19's passage, it showed that his strategy was used to protect himself from harm meanwhile maintaining health. In the face of HIV-related stigma in the Taiwanese society, P10, P16, and P19 were able to hone their attentional and self-adapting skills so that they could enhance their engagement with HAART taking.

To avoid side effects of HAART, P4 and P12 took pills with meals or before sleep. If side effects were unbearable, P8's account below shows his ability to actively communicate with health professionals about his concern, and thus his HAART regimen was changed to another one.

"*At night, our body is repairing. I would take medications before sleep, so the damage caused by the medications can be repaired*." (P4, MSM, 26y)

"*The first time I used a medication, it caused me night sweat. When taking it before sleep, my bed was completely wet in the next morning. I didn't take the medication for long. I asked my doctor to change my regimen*." (P8, Male heterosexual, 49y)

"*After I had my meal and medications, I could taste the medications. It made me feel uncomfortable. Then, later on, I found that when I had the medications after my first bite of the meal, I would feel fine. I found this strategy*." (P12, MSM, 35y)

While some participants had treatment interruption or did not initiate HAART due to its side effects **(Section 6.2.2.1.1.** and **Section 7.2.1.1**.), P4, P8, and P12's accounts show that their experiences of the side effects of HAART did not impede their HAART taking. Rather, they were able to find ways to manage side effects or ask a physician or a nurse specialist to change their regimens.

8.2.2.2.2. Use of external stimuli

In addition to strategies used to protect self from harm and to regularly take HAART, many participants used external stimuli as a means of reinforcing their regular HAART use. For example, the following passages show that participants were able to incorporate HAART into their life by linking dosing times with daily schedules, placing medications at a visible place, using a pill box, setting phone alarms, or significant others' reminding.

Linking dosing times with daily routines:

"*I set my dosing time at night. It helps my bowel movement next morning. I adjust it based on my biological clock. This treatment is not really harmful, as long as you use it appropriately. It can make you even feel better*." (P7, MSM, 30y)

"*Every morning, I would take medications. It becomes part of my life. It is normal. I have to do this. I usually take the two medications and also vitamins*." (P20, Female heterosexual, 36y)

"*When dosing times came, I would take it. At the very beginning, my dosing time was a bit bizarre. I needed to adjust one or two hours forward or backwards all the time. I set my dosing time at 10 pm or 2 am, but I couldn't take my medications on time. Now I have changed it to 12 am. When 12 am arrived, I would remember to take the medications*." (P21, MSM, 35y)

Placing medications at a visible place:

"*Before sleep, I placed my medications near my phone. I would remember to take medications."*(P19, Male heterosexual, 43y)

"*I rarely forget. I usually put my medications in a visible place so that I would be able to notice and take the medications. When dosing times came, I would take it*." (P22, Male heterosexual, 50y)

Using a pill box:

"*When you see your pill box, you would notice if you have taken medications or not. When I opened the pillbox and found I missed one dose, I would take it immediately to make up for it*." (P6, MSM, 52y)

"*At the beginning, I was quite careful. When dosing times come, I would take the medications. I put the pillbox in the room and then I would be able to know if I have taken the medications or not*." (P15, Male heterosexual, 53y)

Setting phone alarms:

"*I use phone alarms to remind myself*." (P9, MSM, 35y)

"*I usually use phone alarms to remind myself of taking medications. When it rang, I would take the medications*." (P17, Male heterosexual, 37y)

Significant others as reminders

"He [her husband] *always reminds me of taking medications."* (P10, Female heterosexual, 33y)

"My wife is my supervisor. Supervising me whether I have taken my medications." (P8, Male heterosexual, 49y)

The aforementioned environmental cues were used by participants to strategically remind them of taking doses. As discussed in **Section 8.2.1.2.**, not every participant was able to consciously manage regular HAART use. However, by setting up an environmental cue or stimulus, participants were able to respond to the cue or stimulus promptly every time it was given. This finding is congruent with "cues to action" emphasised in the HBM for triggering health behaviour (Rosenstock et al., 1988). Likewise, the data in this study revealed that cues or stimuli that could trigger conscious actions played an important role in preventing participants from forgetting doses and in maintaining their HAART taking.

8.3. Discussion

There is considerable theoretical literature that attempts to explain and predict individual health behaviour. However, evidence for the maintenance of health behaviour remains unclear, which is, in part, due to the lack of theoretical elaboration on the behaviour maintenance process following initial behavioural change (Kwasnicka et al., 2016). According to Rotter's social learning theory (1960), the potential for a behaviour (so-called behaviour potential) is directly predicated on the strength of one's drive and need, on the basis of past experience, that the given behaviour can lead to satisfying outcomes. In the same vein, values were found in this study (**Chapter 7**) to act as the driver of participants' HAART-taking behaviour and behavioural

changes. These theoretical expositions all provide a sense that subsequent behaviour changes are triggered and enacted based on one's beliefs and needs at a given time and in the demands of given contexts. To manage long-term HIV treatment, it is crucial to gain insight into an individual's behaviour change and maintenance, and develop strategies to maintaining such behaviour over time and across contexts. However, the existing accounts fail to explain what conditions are required to maintain health behaviour, prevent relapse, and re-establish health behaviour after relapse. The theory of planned behaviour (Ajzen, 1991 and 2002) and Bandura's social cognitive theory (1991 and 2001) stress that behaviour is a function of human cognition with regards intentionality, controllability, and self-regulation. While these theories explain behaviour within the same theoretical constructs as behaviour change, the contents of the constructs may change substantially from behaviour initiation to behaviour maintenance.

In Chapter 6, it was discussed that the value participants placed on regular HAART use can drive initial behaviour change. However, to maintain individuals' regular HAART use, this study found that it requires participants' implementation of conscious actions over the course of their HIV trajectory. Participants' lack of conscious awareness and not incorporating HAART into daily routines were revealed to influence their conscious engagement with HAART taking. Without being consciously aware of HAART taking, participants were inclined to forget doses. This was predominantly common in the situations where they were tired/busy or under the influence of drug psychoactive effects. On the other hand, not incorporating HAART regimens into daily routines also decreased participants' conscious awareness of their dosing times in the demands of given situations. As a consequence, this led to occasionally and unintentionally missing doses among participants who valued HAART taking.

For those who were able to sustain regular HAART use, they tended to have a heightened sense of situational awareness while performing HAART taking, and the ability to self-control and self-adapt. The performance of individual

behaviour needs to be constantly evaluated in an attempt to attain desired outcomes. After initial adoption of HAART-taking, participants evaluated the results of their behaviour. If the results meet their desired outcomes, their behaviour was reinforced (**Chapter 7**). On the other hand, when not meeting participants' needs (e.g. emotion, immediate need of getting fixed), some participants had treatment interruptions. In prevention of this, participants' ability to self-control and self-adapt emerged in the analysis to be an important determinant of enhancing and sustaining their HAART-taking behaviour. The ability to self-control and self-adapt is a continuous process, which needs participants' investment of time and efforts to develop cognitive skills and to mobilise resources.

Participants' HAART taking could vary over time as a result of individual or contextual factors. Thus, for those who could maintain their regular HAART use most of the time, they tended to possess the characteristics of perseverance and determination. With such characteristics, they were more likely to actively control behaviour by being aware of external influences and strategising about what they desired and valued (e.g. giving alternative explanation of HIV medications and use of alarms). In the existing theoretical literature, development of habitual responses has been supported to enhance the maintenance of health behaviour and decrease execution of conscious effort (Hofmann et al., 2008, Verplanken et al., 1999). In this study, it was found that such automatic responses did not sustain the consistency of participants' regular HAART use, particularly when they were not in the state of mind that could keep them attentive to the changing or different environment (e.g. feeling of exhaustion). Instead, participants' ability to develop self-adapting strategies and skills assisted them in managing regular HAART more effectively. As a result, consciously and strategically managing HAART taking enabled participants to fit regular HAART use with the external environment and to achieve sustained performance of regular HAART use regardless of the demands of any given situations.

CHAPTER NINE: DISCUSSIONS, IMPLICATIONS, LIMITATIONS, AND CONCLUSION

9.1. Introduction

To answer the research questions (**Table 10**), in this conclusion chapter, I firstly recapitulate the three major concepts, and discuss how they were linked to influence HIV-positive drug users' long-term management of HAART taking. Due to the impact of participants' illicit drug use on their HAART taking, a comprehensive account of how their illicit drug use interactively influenced their HAART taking is provided. Following the recapitulation of the findings, I will move on to discuss the implications for future research, nursing practice and policy, contribution to knowledge, and limitations of this research.

Table 10: Research questions

Main research question: What are the experiences of taking HAART among HIV-positive drug users? **Four underpinning sub-questions**: 1. What meanings do HIV-positive drug users attribute to their experiences of taking HAART? 2. What is the process of their HAART-taking behaviour? 3. How are meanings of HIV-positive drug users' experiences relating to HAART taking constructed through its process? 4. What contributes to the stability and change of HIV-positive drug users' HAART-taking behaviour? Under what conditions?

9.2. Identity-Values-Conscious Actions Model

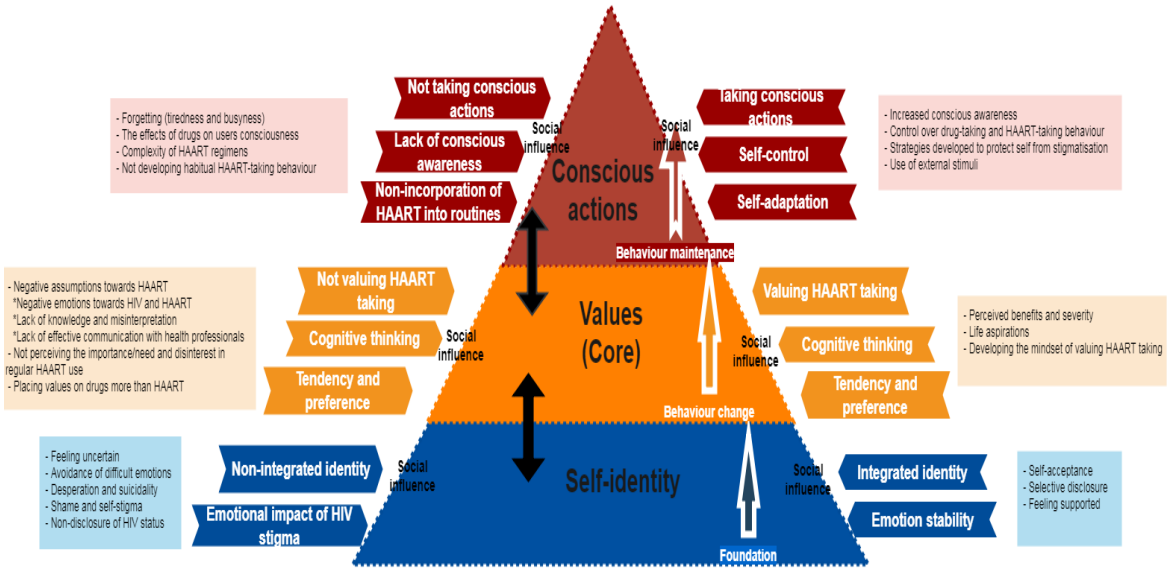


Figure 11: Identity-Values-Conscious Actions Model for sustaining HAART-taking behaviour

This section aims to recapitulate the study findings— HIV-positive identity as part of self-identity, values attached to HAART, and conscious actions, and how these were linked to influence participants' HAART-taking behaviour. As a result, the Identity-Values-Conscious Actions Model was further developed (**Figure 11**).

9.2.1. HIV-positive identity as part of self-identity

The impact of HIV-related stigma on HIV-positive drug users' lives appeared to be profound in this study, emotionally, physically and socially. It has been documented that such impact did not only occur in Taiwan but globally (Batchelder et al., 2013, Chakrapani et al., 2014, McNeil et al., 2017, Mimiaga et al., 2010, Rhodes and Sarang, 2012, Small et al., 2009, Ware et al., 2005). HIV-related stigma is not a singular entity but intersects with other stigmas, such as homosexuality, risky sexual behaviour, illegal drug use, and criminality. These discrediting attributes portrayed by Taiwanese and global societies could pose a negative and significant impact on how HIV-positive drug users perceived themselves as HIV positive, built relationships with others, and managed the health condition (Chakrapani et al., 2014, McNeil et

al., 2017, Mimiaga et al., 2010, Rhodes and Sarang, 2012, Small et al., 2009, Ware et al., 2005).

Identity is defined by Sharma and Sharma (2010) as "*an individual's comprehension of him or herself as a discrete, separate entity* (p.119)." Self-identity is an ongoing process of construction whereby one develops and forms a sense of self through personal experience and social interactions (Karnilowicz, 2010, Stryker and Burke, 2000). In this study, participants' negative perception of HIV infection was deeply grounded in social values, wherein HIV is negatively portrayed by the Taiwanese society. Concerned about living with lifelong and stigmatising HIV condition, the sub-categories pertaining to emotional distress, avoidance coping, heavy drug use and suicidality reoccurred throughout the dataset, particularly in the beginning of HIV trajectory. Reluctance to face and accept HIV positive identity as part of self resulted in the erratic use of HAART and treatment interruption. Taken together, by possessing the new HIV positive identity, it contributed to the disruption of participants' self-identity.

On the other hand, the findings in this study suggested that participants' integration of HIV positive identity into the sense of self laid a solid 'foundation' for facing HIV and managing HAART. With a coherent sense of self-identity, participants were more inclined to be in control of their emotion, think rationally, and be resilient. This notion echoes Pierce and his associates' notion of emotion ownership (2003), which refers to having control over one's emotion. They maintained that having emotion ownership can assist in re-defining the sense of self and expressing it to others (Pierce et al., 2003). In this study, participants' psychological distress was alleviated by their feelings of being supported by, and connectedness, to others and society. Being cared for, accepted, and respected by others enabled them to regain a sense of personal control which is integral to self-concept and self-esteem. These findings resonate with Baumeister's (1999) self-congruence. Self-congruence is defined as self-perception that is in accordance with others' perception of the person (Baumeister, 1999). Self-acceptance and

perceived acceptance from others can decrease internal conflicts, and thus enhance psychological well-being necessary to fulfil self-integration into society, and provide a blueprint for the least conflicted plan of actions (Baumeister, 1999). From these perspectives, this indicates that social connection can facilitate adapting to difficult emotions.

The impact of an illness on individuals' sense of self and lives has been well documented in the theoretical literature (Bury, 1982, Goffman, 1963, Karnilowicz, 2010, Stryker and Burke, 2000). However, far too little attention has been paid to the role of self-identity in influencing an individual's health behaviour. Building on the existing theoretical literature, integration of HIV-positive identity to self-identity emerged in this study as a powerful foundation for HIV-positive participants to connect with others, adapt to negative emotions, and develop positive thinking towards life with HIV and HAART.

9.2.2. Values attached to HAART

Based on the findings, it was revealed that participants' identity formation involved their development of values relating to HAART. As participants viewed HIV as part of their self-identity, they were more likely to value regular HAART use. Integrated identity, therefore, laid a foundation for developing values of regularly taking HAART among participants. However, integrated identity did not necessarily lead to values development in respect to regular HAART use. Some participants accepted themselves as HIV positive but did not value HAART, resulting in erratic HAART use. Values attached to HAART emerged in the analysis to play a core role of driving participants' HAART-taking behaviour. Values are defined, in this study, as a reflection of what an individual deeply believes to be important and necessary. Participants' decision to regularly take HAART is centred around what mattered to them and what they wanted. This is the deep-seated belief that was targeted towards participants' needs and motives for behaviour. The concept of values attached to health is similar to the concept of beliefs elucidated in the HBM (Becker, 1974, Janz and Becker, 1984, Rokeach, 1973, Rosenstock, 1974b). Both concepts convey individuals' beliefs in health. However, compared with

“beliefs”, the concept of values provides a deeper sense of beliefs that can drive individuals’ acts (Rokeach, 1973).

In this study, developing the values of taking HAART involved participants’ perception of its importance and preference to carry out the action, which is formed and reformed through the ongoing process of personal and social experience. At the beginning of HIV trajectory, a lack of knowledge and negative assumptions relating to HAART were surfaced in the analysis to undermine the values participants placed on HAART. By contrast, the acknowledgement of pros and cons of regular HAART could increase the levels of participants’ awareness and subsequently develop the values of taking HAART. In particular, participants’ perception of the risks/consequences of not regularly taking HAART appeared to enhance their awareness. This finding follows closely on from the PMT by Rogers (1975) and Weinstein (1993), with their notion that perceived threats are more likely to increase the probability of selecting adaptive responses compared to perceived rewards.

Preference is another important component, identified in the study, to shape the values participants placed on regular HAART use. Preference conveys the sense of an individual’s tendency to choice, leading to value hierarchy. The hierarchical order of individual values is proposed by Rokeach (1973) to steer sequences of an individual’s acts. In this study, participants tended to prioritise what was important to them. The more an object has value to the participants, the more they preferred it over another. When the values they placed on drug use and regular HAART use were in conflict, some were in favour of pursuing chemsex or injecting drugs but ignored HAART regimens.

An individual’s value can change in its intensity and order over time as a result of the change in personal and social experience. Many participants in this study were able to develop the values they placed on HAART. Having gone through difficult emotions towards living with HIV and HAART, “life aspirations” was found to be inextricably linked with the development of values. Participants’ life aspirations came from their connection with the

social context, thereby giving hopes, meaningfulness, and values in life. The findings are consistent with the results from empirical studies, which showed that acquisition of support from others could enhance their willingness to live longer and motivation to take HAART (Batchelder et al., 2013, de la Hera et al., 2011, Mimiaga et al., 2010, Ware et al., 2005). In that sense, values attached to HAART seemed to be an expression of future orientation and life purposes. By developing the mindset of valuing HAART, it activated participants' desire and motivation of regularly taking HAART.

The role of values in an individual's health behaviour has not been extensively investigated in empirical studies and theoretical literature. Most literature focused on the impact of an individual's beliefs on health behaviour, but did not deeply get into 'values' underpinned in the beliefs. Therefore, this study provides an important opportunity to advance the understanding of this concept and how it can influence individuals' HAART-taking behaviour.

9.2.3. Conscious actions

Placing values on HAART emerged in the analysis to act as a driving force to direct participants' HAART-taking behaviour, whereas to manage and sustain long-term and regular HAART use requires an individual's involvement of consciousness. Consciousness is construed here as a controlled and intentional process where an individual reflects upon mental activity and foster self-control and self-adaptation so as to fit HAART use into external environment and different situations. In other words, participants would need to manage their long-term HIV treatment intentionally and strategically. Bandura's (2001) emphasis of the importance of consciousness in cognitive regulation of action rings true in the analysis of conscious actions in this study.

The findings of this study suggest that without taking conscious awareness to the fore at the dosing times, participants tended to unintentionally forget and miss doses. This was especially common when participants were in the state of tiredness or busyness. In addition, under the circumstances of heavily using drugs, many participants complained about the effect of drugs on

impairing their memory and levels of consciousness. Together, these circumstances seemed to take participants' attention and energy away, subsequently undermining their ability to consciously manage HAART taking. These findings were in line with the results from the existing empirical studies that HIV-positive drug users were more likely to miss doses (de la Hera et al., 2011, Harzke et al., 2004, Mimiaga et al., 2010, Wittveen and Ameijden, 2002). Aside from this, how participants reacted to and dealt with external influences also posed an impact on their HAART taking. Similar to the results from the empirical qualitative literature by Harzke et al. (2004), Mimiaga et al. (2010), and Wittveen and Ameijden (2002), findings from this study revealed that not incorporating HAART regimens into an everyday routine can increase the likelihood of forgetting dosing times. It occurred either due to the complexity of HAART regimens or when not consciously aware of the changing environment and linking HAART taking with the environment. These findings imply that the operation of conscious engagement with HAART taking does not exist in isolation from the external environment. Rather, it required participants to be aware of external influences, and proactively and consciously manage their HAART-taking in the demands of given contexts.

Taking conscious actions to manage regular HAART use involved participants' self-control and self-adaptation to the given situations, and it needed to go through the process of their self-evaluation and self-reflectiveness. By placing high levels of values on regular HAART use, some participants appeared to be determined and persevere. Such deep beliefs and strong willpowers were found to facilitate building the bridge between perceived and actual behaviour control, further developing skills to strategically manage regular HAART use. By consciously and strategically engaging with HAART taking, it enables participants to fit HAART taking with the external environment and sustain their performance of regular HAART use. The empirical literature discussed in **Chapter 4** also indicates that some HIV-positive drug users were able to develop strategies to managing HAART taking (Mimiaga et al., 2010, Ware et al., 2005, Wittveen and Ameijden,

2002). However, these empirical studies did not explore the mechanism underlying their coping behaviour. Thus, the findings in this study can add knowledge to fill the gap in the current evidence base and provide a more comprehensive understanding of HIV-positive drug users' experiences of taking HAART.

9.2.4. Summary

Drawing on the findings, the integration of HIV identity into the sense of self was revealed as fundamental for HIV-positive drug users' self-acceptance. By accepting self as HIV positive, individuals are more likely to face and manage their HIV condition and HAART. However, regular HAART use cannot be explained and predicted solely by an individual's integrated identity. Some participants with an integrated identity did not value HAART and not take it regularly. Instead, the values participants placed on regular HAART use appeared to play a central role in directing and driving their HAART-taking behaviour. Valuing HAART involves that an individual perceived its importance and has the tendency to take it regularly. Once participants placed the values on regular HAART use, they were inclined to feel motivated in taking HAART, leading to behaviour changes. However, this study found that to maintain regular HAART use required participants' conscious engagement with HAART taking. HAART is a long-term treatment which requires individuals to strictly follow treatment regimens. To sustain the performance of regular HAART use, participants' self-control and self-adaptation were particularly found to help manage their HAART taking consciously and strategically.

9.3. Participants' experiences of taking drugs and HAART

A number of empirical studies reported that active drug use could greatly and negatively influence HIV-positive drug users' HAART taking (Arsten et al., 2002, Azar et al., 2015, Bouhnik et al., 2002, Carrieri et al., 2003, French et al., 2011, Hayashi et al., 2016, Hicks et al., 2007, Hinkin et al., 2007, Jordan

et al., 2014, Joseph et al., 2015, Kalichman et al., 2015, Magidson et l., 2015, Mellins et al., 2009, Moore et al., 2012, Palepu et al., 2006, Roux et al., 2008, Sharma et al., 2007, Wood et al., 2004). However, the interplay between drug use and HAART use among this group of the population remains unclear in the current evidence base. In this study, participants' drug use was revealed to be linked to their emotion, values, and self-control. These have been discussed under each concept, and thus the focus of this section is to recapitulate the findings and provide a comprehensive understanding of the collective and interactive effects of drug use on HIV-positive drug users' HAART-taking behaviour.

Participants' drug use appeared to be closely linked to their emotion. During the HIV trajectory, many participants had experienced difficult emotions due to HIV-related stigma and family crisis. In the same vein, to date, several lines of evidence have revealed HIV-positive drug users' experiences of emotional distress due to stigmatisation and a lack of support (Batchelder et al., 2013, Chakrapani et al., 2014, McNeil et al., 2017, Mimiaga et al., 2010, Witteveen and van Ameijden, 2002). Building on the results of the previous studies, some in this study were inclined to adopt avoidance coping, such as denial and drug use, instead of facing the difficulties. Illicit drugs were reported by participants to provide pleasure and healing effects. In response to stress, some used drugs to fill a void of emptiness and to obtain happiness and avoid stress. This is congruent with Anderson's (2003) notion that when situations do not meet one's choice, the person could avoid the situations in hopes of mitigating difficult emotions. Aside from drug use as a coping strategy, it was evident in this study that participants' physical and psychological dependence on drugs can also influence their drug-taking behaivour. With the experience of drug dependence, it interfered with participants' judgement and increase the likelihood of engaging in risky behaviours, such as chemsex and injecting drug use, in an attempt to get fixed and soothe anxiety. These risky behaviours were found to greatly disrupt participants' lifestyle and dosing schedules. As a result, it impeded their access to care and HAART taking. The illegality of drugs and police

interference were found to widen the accessibility gap of HIV care among drug users. Such a structural barrier has also been documented in Mimiaga's study (2010).

Drug use affected the values participants placed on HAART. In particular, when participants' lifestyle and HAART-taking were in conflict, some placed an emphasis on drugs more than HAART in pursuit of euphoric effects. Values represent individuals' preference, and the hierarchical order of values can influence individuals' sequence of acts (Rokeach, 1973). In addition, drugs were revealed by participants to have the effects of changing and distorting their thinking and perception, leading to the rationalisation of drug-taking and decreased self-awareness of HAART taking. Drugs, therefore, became some participants' main focus and immediate need, and thus they were less likely to care about their health and HAART. Given the addictive effects of drugs, current literature suggests the effectiveness of methadone on decreasing frequency of drug use and promoting drug users' HAART-taking (Azar et al., 2015, Hicks et al., 2007, Joseph et al., 2015, Lambers et al., 2011, Lappalainen et al., 2015, Lee et al., 2016, Nolan et al., 2011, .Palepu et al., 2006, Roux et al., 2008, Turner et al., 2003). Nonetheless, the findings of this study pointed out that whether methadone could effectively treat drug users' addiction and enhance HAART taking depends on where individuals' values lie. This implies that individuals' deep beliefs are key to managing HAART taking.

While drug use might affect one's HAART taking, the findings suggest that it is possible to regularly take HAART while still engaging in drug use as long as individuals can control themselves over their behaviour. Psychoactive drugs impaired an individual's memory and conscious awareness of behaviour and lead to forgetfulness, especially when heavily using drugs. However, by taking control from overly indulging in drugs, participants appeared to be able to consciously manage their HAART-taking. In the existing theoretical literature, most of the focus has been on perceived behaviour control (Ajzen, 1985, 1991 and 2002, Bandura, 1991 and 2001,

Rosenstock et al., 1988). However, the literature has not clearly explained how perceived behaviour control is translated into actual behaviour control. In this study, it was found that putting thought into action with regards regular HAART use requires individuals to place values on HAART and the implementation of conscious actions. As a consequence, individuals are more likely to have the ability to manage their drug use and long-term HIV treatment.

9.4. Implications

9.4.1. Implications for nursing practice

Nurses play a crucial role in supporting HIV-positive drug users during their treatment process, and often have a close connection to them. Thus, it is important to use this communication line to address common barriers to taking HAART. At the beginning of HIV trajectory, many participants experienced emotional distress. This finding suggests that upon diagnosis of HIV, nurses need to pay a particular close attention to HIV-positive drug users' psychological well-being by eliciting HIV-positive drug users' concerns, feelings, and self-perception of being HIV positive and taking HIV medications. This study offers evidence that patients' sense of self can be also affected by the social context where feelings and thoughts arise. Thus, assessing HIV-positive drug users' support system, including family, friends, partners and community resources, can facilitate understanding their support sources and identifying the underlying issues that can potentially influence their emotion and HAART taking.

HIV disclosure was found to help increase the chance of obtaining support. However, this is one of the major challenges that HIV-positive drug users encountered when attempting to gain support. The findings in this study suggest that nurses should 1) encourage patients to reflect on and understand their emotions, 2) understand patients' support system, 3) educate patients about the importance of self-disclosure, 4) support patients to develop strategies for HIV disclosure and acquisition of support, 5) be an

educator for and a mediator between patients and their family if patients agree, 6) provide referrals and community support resources to meet patients' individualised needs. Together, by providing individualised care and integrated services, this can assist HIV-positive drug users in connecting with people and society, and enhance their feelings of self-worth, connectedness, and hopefulness and meaningfulness of living with HIV and HAART. It is recommended to help patients face and deal with their emotions first, and then to assist them in making rational decisions and developing strategies to emotion regulation in replacement of avoidance coping.

The findings brought important implications that values attached to HAART are the driver of HIV-positive drug users' HAART-taking behaviour. Nevertheless, helping HIV-positive drug users to develop values of HAART might take time. The reasons behind it are that it takes time for HIV-positive drug users to perceive the importance of regular HAART use, and to develop the mindset of valuing it. Thus, this study recommends nurses to regularly assess HIV-positive drug users' needs, and provide education and emotional support throughout the treatment process. Peer support and educator groups should also be facilitated by nurses to provide support and advice on practical issues HIV-positive drug users commonly encountered, and develop a sense of community. In doing so, it allows HIV-positive drug users to gain insight into the pros and cons of regular HAART use, and increase their awareness of its importance. Before and at the beginning of receiving new HAART regimen, side effects emerged in the analysis to be one of the major concerns among HIV-positive drug users. It is suggested to provide sufficient information before initiation of HAART. This can enhance their readiness of taking HAART and minimise their misinterpretation of it.

The meaning of regular HAART use is constructed through HIV-positive drug users' interaction with others and how they perceive themselves and the world. Part of the treatment journey involves HIV-positive drug users' gradual discovery and development of values attached to HAART. In that sense, it implies the importance of providing constant support to this group of the

population with patience, non-judgemental attitude, and compassion. Commenting on this, the findings of this study provide support for the premise that nurses should educate and guide drug users by using motivational interviewing techniques (Miller and Rollnick, 2012). Motivational interviewing is defined as "*a collaborative conversation style for strengthening a person's own motivation and commitment to change* (Miller and Rollnick, 2012, p.12)." In addition to the use of these communication techniques, provision of support from spirituality and religion can also play a powerful role in helping HIV-positive drug users to develop the values of regular HAART use, and strengthen their will to make behaviour changes.

Concerning the need for long-term management of HAART taking, forgetting to take doses was common among HIV-positive drug users in this study. This was mainly due to their tiredness/busyness, non-incorporation of HAART into everyday life, changes of environment, or drug effects. To minimise external influences, the findings in this study suggest that nurses should regularly evaluate the values HIV-positive drug users placed on regular HAART use, and assess their ability to self-control and adapt in response to contingencies.

9.4.2. Implications for policy

To resonate with Sustainable Development Goals (SDGs) plan of action (UN, 2015, UNODC, 2016), the findings in this study suggest building a strong link between police authority, health services, and social services. Criminalisation of drug use and fear of police interference can greatly influence HIV-positive drug users' decision to access HIV and addiction services. This study suggests to add the role of police officers as a gatekeeper, providing referrals to health and social services. By integrating police support services into health and social services, it can help to engage this hidden population in the integrated health and social care, and optimise their health outcomes

A number of HIV-positive drug users in this study experienced psychological issues and stigmatisation. It is suggested that mental health services for this group of the population should be operated at the national level and added

as part of HIV care. While policy pertaining to anti-HIV stigmatisation is enacted, HIV-related stigma remains prevalent in Taiwan. It is important to extensively promote HIV education in communities, including schools, prison settings, and other public areas, with the aim to decrease public assumption/prejudice towards HIV-positive drug users.

Although the number of female HIV-positive drug users is small among the HIV population in Taiwan, a lack of addiction service provision that is tailored to meet female HIV-positive drug users' needs could leave them more vulnerable to the impact of gender inequality. Drug use can pose an impact on access to HIV care and HAART taking among HIV-positive drug users. To enhance female drug users' access to HIV care, issues relating to their problem drug use should be tackled. In that regard, this study offers suggestive evidence for the provision of addiction services that are gender responsive in Taiwan.

Furthermore, this study suggests that the Identity-Values-Conscious actions model can serve as a guide for the national government to understand elements of the model of behaviour change and maintenance in HIV-positive drug users.

In short, national government plays a key role in creating an inclusive and non-discriminatory society for people with all backgrounds, including HIV-positive drug users. By integrating them into society, it can enhance their sense of community, decrease the likelihood of engaging in risky behaviour and crimes, and optimise health at the individual and public health levels.

9.4.3. Implications for future research

During the course of this research, a few questions emerged which would be valuable to be examined further in future research.

The expositions of HIV-positive drug users' HAART-taking are unsatisfactory in the current evidence base. It is recommended to study HIV-positive drug users' HAART-taking in different social contexts and understand their experiences through a theoretical lens. The conceptual model developed in

this study could serve as a point of reference for understanding HIV-positive drug users' experiences of taking HAART in future research projects. In addition, it is worth suggesting research to test this model.

In this research, no difference in HAART taking among males, MSM, and females was identified. However, there were only a few female HIV-positive drug users recruited in this study. Thus, an implication of this study limitation for future research is to focus on female HIV-positive drug users and to see if there are any gender differences in HAART taking among HIV-positive drug users. In addition, this research did not involve the families of HIV-positive drug users. Family is often one of the important aspects in HIV and addiction care. It is suggested to understand drug users' drug use and HAART taking from their families' perspectives. This can provide a fuller picture of drug users' and their families' concerns about HIV, HAART, and drug use, and further develop a more comprehensive and tailored adherence interventions that meet affected individuals' and their families' needs.

Values emerged in the analysis to be the core category, whereas the concept of values is under-researched in the field of health behavioural research. The findings in this study have significant implications for understanding this concept in future behavioural research. The constructs of values developed in this study and the exposition of values in Rokeach's (1973) work could be taken into account.

9.5. Contribution to knowledge

In addition to the provision of some direction for future research, this study has made three major contributions to the current literature.

Firstly, this is the first qualitative study exploring HIV-positive drug users' experiences of taking HAART in the developed country in Asia. Concerned with the difference in culture between Eastern and Western countries, the way people perceive HIV, HAART and drug use in Asian contexts might differ from those from Western countries. In that sense, the findings of this study

can extend our knowledge of the mechanism underlying HIV-positive drug users' risk and health behaviour within Asian social contexts.

Secondly, this study, for the first time, developed a conceptual model used to understand HIV-positive drug users' experiences of HAART-taking, including behaviour changes and behaviour maintenance. The model of this study can be further examined in other social context and refined to fit in different contexts. This model can also be used in the future to develop an adherence assessment tool and associated adherence interventions.

Finally, this is the first conceptual model developed and used to understand drug users' experiences of drug use as well as HAART use in Taiwan and internationally. When delivering interventions, nurses should assess HIV-positive drug users' drug use problems as well as adherence to medications. Having said that, this model can offer valuable insight into the interplay between HIV-positive drug users' risky behaviour and health behaviour.

9.6. The impact of findings

The research findings and further development of associated interventions will be written in reports and articles, and be disseminated to hospitals and NGOs involving in HIV and addiction care in Taiwan. As such, it may assist service providers in developing the competence to deliver adherence interventions to meet HIV-positive drug users' needs. Aside from the workshops, findings will also be disseminated to peer-reviewed journals and conferences. Policy makers will be invited to join a roundtable discussion to explore the impact of current policies on drug users' adherence to HAART, and how to move forward to enhance drug users' health behaviour as well as potential for impact on their families/significant others.

With regards the implications of the findings discussed in **Section 9.4.**, workshops and training in relation to adherence to antiretroviral treatment could be delivered to service users, providers and families/significant others. In addition to these workshops interactive workshops could be delivered to

HIV-positive drug users to develop lay summaries of the findings, and to obtain their ideas and thoughts about how to shape associated adherence interventions, strategies and services. Appropriately targeted panel discussions and events could also be undertaken to relevant stakeholders in the fields of HIV and addiction, aiming to present and discuss the lay summaries of the research findings and further develop future research priorities related to adherence interventions/strategies based on the findings.

9.7. Limitations

While this study can make contributions to knowledge within the field of HIV, addiction, and behavioural research, there are limitations.

Firstly, the aim of this study is to develop a conceptual model that can enhance understanding HIV-positive drug users' experiences of HAART-taking. However, during data collection, there were challenges of finding female HIV-positive drug users due to a small number of this subgroup in Taiwan (N=913) (CDC, 2017), and the possible influence of social expectation towards the female gender. Only three female participants were recruited in this study. Thus, the findings in this study may not be able to fully convey female HIV-positive drug users' experiences of taking HAART.

Secondly, findings of this study indicated the impact of social support and social stigma on participants' sense of self and value development. However, structural factors, particularly infrastructural factors (e.g. accessibility of HAART), were not identified within the findings, and were not found to be the main concern for the majority of participants. It is acknowledged however that structural factors have been found to be relevant to individuals' health behaviour (**Chapter 2: Literature review**) as supported by the Behavioural Change Wheel proposed by Susan Michie (2011). Future research building on the findings of this study, in the Taiwanese culture, could look to take account of this element and explore its impact on individuals' adherence to HAART. Despite this being a possible limitation of the study, the conceptual framework developed in this study does provide useful insight with the

potential of being transferred to other social contexts, offering opportunities to explore and examine the structural element that was less focused and evident in this thesis.

Thirdly, in the literature review, ‘substance’ misuse was not included in the search terms due to my concerns over its broad definition (as opposed to the specific focus of this review on drugs) and a large number of relevant quantitative studies identified in the databases. Nonetheless, not including ‘substance’ in the search could lead to omitting articles that are relevant to drug users’ adherence to HAART. Therefore, it would be worth including ‘substance’ in the search in future research to maximise the chance of finding relevant studies.

Fourthly, this research drew on grounded theory approaches to explore drug user’s experiences of taking HAART, and to further develop a conceptual model that facilitates understanding their behaviours. Whilst recognising that other approaches could have been used such as phenomenology to explore drug users’ experiences considering that its aim is to understand the meanings of participants’ stories (Breakwell, 2004), the rationale for using grounded theory was related to the focus on theory development through understanding individuals’ experiences. Therefore, in order to move beyond understanding, drawing on grounded theory approaches was considered the most appropriate.

Fifthly, this study relies on participants’ self-report, social desirability bias and recall bias may become issues (Van de Mortel, 2008). To minimise the taken-for-granted assumptions, reflexivity was employed throughout the study process, where I wrote research memos to document the research decisions I made and my reflection on the research process.

Sixthly, in this study, data were analysed by only one researcher, SS, which could potentially bring researchers’ assumptions into analysis and misinterpret the findings. However, the use of memo writing and Professor

Aisha Holloway and Dr Rosie Stenhouse's supervision of this study enhanced the transparency of the study process (Charmaz, 2014).

Last but not least, concerned about small sample size, the use of convenient and purposive sampling in this qualitative study, the findings cannot be representative of HIV-positive drug users in Taiwan (which is often the limitation of qualitative research) (Gerrish and Lacey, 2010). However, the provision of a thick and rich description of participants' experiences of taking HAART in this study allows other researchers to evaluate the applicability of the data to other contexts, which can enhance transferability (Polit and Beck, 2008).

9.8. Conclusion

To conclude, this study aims to deeply explore HIV-positive drug users' experiences of taking HAART and subsequently develop a conceptual model that can help to understand their experiences of HAART-taking in the Taiwanese context. Though it has been documented that HIV-positive drug users were less likely to adhere to HAART compared to the general HIV population, the mechanism underlying such behaviour remained unclear. This study should prove to be particularly valuable to advance understanding HIV-positive drug users' HAART-taking. The key strengths of this study are 1) the in-depth understanding of HIV-positive drug users' experiences of HAART taking and illicit drug use in Taiwan, 2) the further acknowledgement of how HIV-positive drug users' illicit drug use interactively influenced their HAAR-taking behaviour, and 3) the development of Identity-Values-Conscious actions Model that can be applied to understand HIV-positive drug users' behaviour changes and maintenance. Taken together, these findings can provide implications 1) for nursing adherence assessment and associated interventions targeting this group of HIV population, 2) for the enactment of health and social policies that can create peaceful, just and inclusive society for this vulnerable group, and 3) for future research to

develop a more robust health behaviour model and evidence-based interventions for HIV-positive drug users.

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Appendices

Appendix 1: Socio-demographic information

(* means often missing doses now, ** means often missed doses in the past, ***tend to regularly take medications throughout)

Code number	age	gender	Transmission route	Education level	Main support source	Source of income	Current or past drug users	Illicit drug use	Routes of drug use	Length of drug use	Frequency of drug use	Ever had MMT, NEP, or detoxification Treatment	How long have you been diagnosed with HIV?	How long have you been on HAART
1*	28	MSM	Sex	High school or equivalent	Family	family and self	Current	Amphetamine (snorting, injecting), Ecstacy (po)	Oral, snorting, injecting	3-5 years (4 years)	4-6 times /week	No	4 years	4 years
2*	32	MSM	Sex	College	Health professionals,friend	Self	Current	Amphetamine (snorting), Ecstacy (po)	Oral, snorting	1-3 years	<1 次/week	No	6-7 years	6-7 years
3*	37	MSM	Sex	College	Family	Self	Past	Amphetamine (snorting), MDMA (po), Marijuana (smoking), Ketamine (snorting)	Oral, snorting	6-7 years	2-3 次/week	No	6-7 years	6-7years

4**	26	MSM	Sex	College (not completed)	Family	Self	Past (last time was 2 months ago)	Amphetamine (snorting), MDMA (snorting)	Snorting	Amphetamine (for around 7-8 months, Last Nov, 2014 to this June, 2015), MDMA (Used only 4-5 times 3 years ago)	4-6 次/week	No	3-4 years	2 years
5***	45	Male heterosexual	Needle sharing	less than high school	Self	Self	Past	Heroin (injecting), Amphetamine (snorting)	Injecting, snorting	Heroin(20 years), amphetamine (21 years)	>10 times /week	No	8 years	2 years
6***	52	MSM	Sex	College	Self (living alone)/NGOs	Self	Past	Heroin (Sub), Marijuana (smoking), Ketamine (snorting)	Subcutaneous injection, smoking, snorting	Heroin (4months ago, used only 6 times), Ketamine (5 years ago, used for 2-3 years)	> 7 times/week	No	16 years	15 years
7**	30	Male (Past: MSM; current: bisexual)	Sex	College	Family (parents)	Self	Past (Last time was half year ago)	Amphetamine (snorting), MDMA (snorting)	Snorting	Amphetamine (2-3 years, stopped half year ago); MDMA (5-6 years, Stopped 2-3 years ago)	1-3 times/month	No	5-6 years	5-6 years
8***	49	Male heterosexual	Needle sharing	High school or equivalent	Family (wife)	Wife	Past	Heroin (injecting), Amphetamine (snorting), Marijuana (smoking) (1991-2004); Opioid	Oral, snorting, and injecting	Heroin (13 years), Amphetamine and Marijuana (1991-2004); Opioid and Cocaine (2 months)	>10 times /day	No	11 years	10 years

								(smoking) and Cocaine (po) (2 months in between)						
9**	35	MSM	Sex	College	Family and partner	Self	Current	Amphetamine (Snorting), MDMA (po), Ketamine (snorting)	Oral, snorting	5 years	Once/ 2 weeks	No	7 years	3 years
10***	33	Female (Past: Bisexual; current: heterosexual)	Needle sharing	High school or equivalent	Family	Self and partner	Past	Heroin (Smoking and IV), Amphetamine (snorting), MDMA (po), Marijuana (smoking)	Oral, smoking, snorting, injecting	> 5 years	> 10 times/ day	MMT, drug detoxification	10 years	5 years
11***	31	MSM	Sex	College	Family	Family	Past	Amphetamine (snorting), Ketamine (smoking), MDMA (po), Marijuana (smoking)	Smoking, snorting, oral	3 years	1 time/ week (most frequent: 4 days/week)	Yes (Involuntary hospitalisation for psychiatric symptoms)	4 years	4 years
12*	35	MSM	Sex	Postgraduate (Master)	Family	Self	Current	Amphetamine (Snorting), Ketamine (snorting), MDMA (po)	Snorting, Oral	Amphetamine (1 year), MDMA (6 years)	Amphetamine: 1 time/ week or 2 weeks, MDMA and Ketamine: 1 time/ month	No	2 years	2 years

13**	31	MSM	Sex	College	Family	Family	Past	MDMA (po), Ketamine (snorting), Marijuana (smoking), Amphetamine (snorting)	Oral, snorting, smoking	MDMA (2002-2005), Ketamine (2002-2014), Marijuana and Amphetamine (rarely used)	MDMA (1-2 times/week), Ketamine (4-6 times/day), Marijuana and amphetamine (less than 5 times in his life)	No	6-7 years	3 years
14**	36	MSM	Sex	College	Family	Family	Past	MDMA (po), Ketamine (snorting), Amphetamine (snorting)	Oral, snorting, smoking	MDMA (10 years, 22Y-32 Y), Ketamine (14 years, 22Y-Nov, 2015), Amphetamine (2-3 times in his life)	MDMA (3 times/month), Ketamine (more than 4-5 times/ day)	No	6 years	4 years
15*	53	Male heterosexual	Sharing diluting water	High school or equivalent	Family (sister and son)	Family	Past	Heroin (IV), Amphetamine (snorting)	IV, snorting	Heroin (13 years, 1994-2007), Amphetamine (22 years, 1985-2007)	Heroin (more than 10 times/day), Amphetamine (more than 10 times/day)	Yes (clinics and hospital for drug detoxification treatment) –didn't work for him (he was a heavy heroin user)	9 years	7 years

16**	42	Male heterosexual	Needle sharing	Less than high school	Family	Family	Current	Heroin (IV), Amphetamine (snorting), Ketamine (Snorting)	IV, snorting	Heroin (20 years), Amphetamine (20-30 years), Ketamine (1 or 2 times/lifetime)	3-4 times/day	Yes (drug detox and methadone). It doesn't work for him. He still keep using heroin	10 years	started 3-4 years ago (Have taken for three years) -> treatment interruption -> restarted 1 year ago (have taken for one year)
17***	37	Male heterosexual	Tatoo equipment	less than high school	Family	Self	Current	Heroin (IV), Amphetamine (smoking)	IV, smoking	Heroin (13 years); Amphetamine (23 years)	Heroin (past: 15 times/day; current: 2 times/week). Amphetamine (2 times/week)	Methadone (current), needle exchange programme (current), suboxone (current)	13 years	5 years
18*	32	Female	Sharing diluting water	High school or equivalent	Family	Partner	Past	Heroin (IV), MDMA (Po), Cocaine (snorting), Amphetamine (snorting and IV),	IV, po, snorting	Heroin (2-3 years), Amphetamine (4-5 years), Cocaine (1 time), MDMA (3-4 times)	Heroin (5-6 times/day), Amphetamine (1-2 times/week)	No	8 years	(In her first pregnancy, she took it for 10 months -> stop-> in jail for 7 years -> Recently out of jail, then pregnant, took one-month HAART-> abortion-> stop Tx)

19***	43	Male heterosexual	Sharing needles	High school or equivalent	Family	Self	Past	Heroin (IV), Amphetamine (Snorting)	IV, snorting	Heroin (3 years), Amphetamine (11 years)	Heroin (2-6 times/day), Amphetamine (Occasionally)	No	8 years	10 months
20***	36	Female	Sharing needles	High school or equivalent	Family and husband	Self	Past	Heroin (IV), amphetamine (snorting), marijuana (smoking), Ketamine (snorting), MDMA (po)	IV, snoritng, po, smoking	Heroin (2-3 years), amphetamine (10 years, intermittently), Ketamine, marijuana, MDMA (few times)	Heroin (2-10 times/day), amphetamine (1-2 times/day), others (few times in life)	Yes (take sedatives prescribed by a clinic, physical symptoms were alleviated) Afterwards, she still used drugs.	12 years (2004)	3 years (since 2013)
21***	35	MSM	Sex	MSc	Family and friends	Family	Current	Amphetamine (snorting), MDMA (po), Cocaine (snorting), Marijuana (smoking)	Snorting, IV, po, smoking	Amphetamine (more than 6 years), MDMA (half year), Marijuana (2 years), Cocaine (few times)	Amphetamine (Past: 3 times/week; Current: everyday)	No	2 months	2 months

22*	50	Male heterosexual	Needle sharing	less than high school	Self	Welfare and part-time job	Current	Heroin (injecting), amphetamine (snorting)	Snorting and IV	Heroin (3-4 years), amphetamine (since 30s. Intermittently but now stopped)	Heroin (now 2 times/day)	Methadone (2 months), Needle exchange programme (current, 3 years, peer delivery of free needles to current drug users), suboxone (past, he said it did work two years ago, but it doesn't work now due to his heavy drug use.	2004 (12 years)	He was in and out of jail for drug use and engagement with illegal activities and thus he didn't' receive Tx. Started Tx for almost a year due to deterioration of health (since last June or July)

Appendix 2: Summary of theories/models in relation to health behaviour

Theory/model	Core constructs
Health Belief Model (HBM) (Becker, 1974, Janz and Becker, 1984, Rosenstock, 1974a and b)	The HBM was spelt out in terms of four constructs ➢ Perceived susceptibility ➢ Perceived severity ➢ Perceived benefits ➢ Perceived barriers Added concept: Cues to actions, self-efficacy
Information-motivation-behavioural skills model (IMB Model) (Fisher and Fisher, 1992 and 2002)	Health outcomes <- Health behaviour <- Adherence behavioural skills <- Information + Motivation Moderating factors: social factors
Protection motivation theory (Rogers, 1975, Weinstein, 1993)	Three components determining the intensity of protection motivation (Rogers, 1975): ➢ The magnitude of harm of a depicted event ➢ The probability of that event's occurrence ➢ The efficacy of the protective response ➢ Self-efficacy A Revised version of protective motivation (Weinstein, 1993): ➢ Threat appraisal – Severity and vulnerability – Intrinsic rewards ➢ Coping appraisal – Response efficacy – Response costs Use costs and benefits of the existing or recommended behaviour to predict the likelihood of change

Theory of planned behaviour (Ajzen, 1985, 1991 and 2002)	Behaviour: ➢ Behavioural intention – Attitude towards actions ▪ Beliefs about the outcomes of the behaviour ▪ Evaluation of expected outcomes – Subjective norms ▪ Normative beliefs ▪ Motivation to comply ➢ Perceived behavioural control – Control beliefs
Health Locus of Control (HLC) (Rotter, 1966)	➢ Internal locus of control: A belief that life can be controlled ➢ External locus of control: A belief that life is controlled by external factors that cannot be controlled by the individual or chance/fate controls an individual's life
Social cognitive theory: from Self-regulation perspective (Bandura, 2001)	Structure of self-regulation system: ➢ Self-monitoring: it refers to how an individual's performance is self-monitored and cognitively processed ➢ Judgement: An individual's standards for guiding behaviour ➢ Self-reactiveness: An individual's affective reaction that can lead to motivating behaviour ➢ Self-efficacy
Agency (Bandura, 1999)	Four main features: ➢ Intentionality ➢ Forethought ➢ Self-Reactiveness ➢ Self-reflectiveness
Transtheoretical model (Prochaska and Velicer, 1997)	Involves six stages of change – Precontemplation, contemplation, preparation, action, maintenance, and termination. ➢ At the pre-contemplation stage, individuals are not intending to change their behaviour, typically it occurs in the first 6 months. Their lack of intention tends to be due to a lack of awareness. ➢ Contemplation is the next stage, where individuals are more aware of pros and cons of changing behaviour, and are intending to take action but not committing to doing so.

	➢ At the preparation stage, individuals are intending to change behaviour in the immediate future. Typically, individuals already have taken some significant actions in order to change behaviour, such as gathering information of concerns. ➢ At the action stage, individuals are actively engaging in making a change in their behaviour. ➢ At the maintenance stage, individuals are attempting to maintain their behaviour change, which starts 6 months after change (action). ➢ The termination stage is the stage where individuals have zero temptation to drop out of behaviour change.

Appendix 3

Summary of the included quantitative studies (N=40)

	Method	Authors /Project period	Sample size	Sample	Sampling	Measure of adherence	Results
Canada	An ongoing prospective observational cohort study conducted in Vancouver since 1996	Azar et al. (2015)/(1996-2013) Title: Drug use patterns associated with risk of non-adherence to antiretroviral therapy among HIV-positive illicit drug users in a Canadian setting: A longitudinal analysis	N=692	HIV-positive illicit drug users	Convenient sampling Snowball sampling	Pharmacy dispensation record The ratio of number of days the patients received HAART refills/Total number of days of medical follow-up	Heroin and cocaine use was associated with lower likelihoods of optimal adherence (≥95% adherence rate); MMT was associated with greater likelihood of adherence. 51% of the participants were categorised by ≥95% adherence.
		Hadland et al. (2012) /(1996-2008) Title: Young Age Predicts Poor Antiretroviral Adherence and Viral Load Suppression	N=545	HIV-positive IDUs	Convenient sampling	Pharmacy dispensation record	Follow-up period: 8.5months to 91.6 months. Adherence rate was significantly lower among young IDUs. Adherence is a mediator of the relationship

		Among Injection Drug Users					between age and viral load suppression 66 (33.8%) discontinued ART during follow-up period. There were 26.6% periods in which individuals were more than 95% adherent in 4460 observations
		Hayashi et al. (2016) / (2005-2013) Title: Factors associated with optimal pharmacy refill adherence for antiretroviral medications and plasma HIV RNA nondetectability among HIV-positive crack cocaine users: a prospective cohort study	N=438	HIV-positive crack cocaine users	Convenient sampling	Pharmacy dispensation record	54.8% of the participants exhibited optimal pharmacy refill adherence (≥ 95%) in the previous 6 months. 89% attained ≥95% adherence at some point during the study period. Older age and higher CD4 count were associated with optimal adherence. Daily Cocaine and Heroin use and homelessness was negatively associated with optimal adherence

		Lappalainen et al. (2015) / (2005-2013) Title: Dose-response relationship between methadone dose and adherence to antiretroviral therapy among HIV-positive people who use illicit opioids	N=297	HIV-positive individuals who use opioid	Convenient sampling Snowball sampling	Pharmacy dispensation record	Median follow-up period: 42.1 months MMT dose > 100mg per day was associated with optimal adherence (≥95% adherence rate)
		Joseph et al. (2015) /(1996-2012) Title: Factors linked to transitions in adherence to antiretroviral therapy among HIV-infected illicit drug users in a Canadian setting	N=703	HIV-positive illicit drug users	Convenient sampling	Pharmacy dispensation record	27% of the participants (n=190) had optimal adherence. Transition out of optimal adherence (≥ 95%) was associated with younger age, periods of homelessness, active injecting drug use, and incarceration. Individuals who transitioned into optimal adherent were older. Periods of sex work and injecting drug use were

							barriers to becoming optimally adherent. MMT was associated with optimal adherence and had a protective effect against being non-adherent.
		Mann et al. (2012) /(1996-2009) Title: Improved adherence to modern antiretroviral therapy among HIV-infected injecting drug users	N=682	HIV-positive IDUs	Convenient sampling	Pharmacy dispensation record	The proportion of achieving at least 95% adherence increased over time from 19.3% in 1996 to 65.9% in 2009. Initiation year was associated with ≥ 95% adherence.
		Nolan et al. (2011) /(1996-2008) Title: Adherence and plasma HIV RNA response to antiretroviral therapy among HIV-seropositive injection drug users in a Canadian setting	N=267	HIV-positive IDUs	Convenient sampling	Pharmacy dispensation record	17-95months of follow-up. 30% of the 267 participants had ≥ 95% of adherence during the first year of ART. ≥95% adherence, participation in MMT, and older age, year of ART initiation was positively associated with viral suppression.

		Palepu et al. (2006) / (1996-2003) Title: Antiretroviral adherence and HIV treatment outcomes among HIV/HCV co-infected injection drug users: The role of methadone maintenance therapy	N=278	HIV/HCV co-infected IDUs	Convenient sampling	Pharmacy dispensation record	129 out of 278 had ≥ 95% adherence 36.76 months of follow-up Enrollment in MMT is associated with reduced heroin use and improved adherence
		Palepu et al. (2011) / (1996-2008) Title: Homelessness and Adherence to Antiretroviral Therapy among a Cohort of HIV-Infected Injection Drug Users	N=545	HIV-positive IDUs	Convenient sampling	Pharmacy dispensation record	26.6% had ≥ 95% adherence Follow-up duration: 23.8 months (8-91 months) Homelessness and frequent heroin use were negatively associated with optimal adherence (≥ 95%), whereas MMT was positively associated.
		Lee et al. (2016) /(2005-2013) Title: Psychosocial Factors in Adherence to	N=667	HIV-positive IDUs	Convenient sampling	Pharmacy dispensation record	85.9% of 650 participants achieved 95% or greater ART adherence at

		Antiretroviral Therapy Among HIV-Positive People Who Use Drugs					some point during the study period. In multivariable analyses, factors positively associated with 95% or greater ART adherence included adherence self-efficacy, age, current enrollment in MMT, and CD4 cell count, while drug use patterns and negative outcome expectancy were negatively associated with optimal adherence to ART.
		Ti et al. (2014)/ (1996-2012) Suboptimal plasma HIV-1 RNA suppression and adherence among sex workers who use illicit drugs in a Canadian setting: an observational cohort study	N=587	HIV-positive sex workers who use illicit drugs	Convenient sampling	Pharmacy dispensation record	18-60 months follow-up Average adherence rate was 50% Adherence mediated the relationship between sex work and suppression of viral load

	Prospective cohort study in Vancouver	Wood et al. (2004) Title: Elevated rates of antiretroviral treatment discontinuation among HIV-infected injection drug users: implications for drug policy and public health	N=1422	HIV-positive individuals (non-IDUs and IDUs)	Convenient sampling	Discontinuation was defined as the first day of a ≥3-month period without receiving any antiretrovirals	359 were IDUs (25.3%). History of injection drug use was associated with more rapid discontinuation of therapy At 12 months of after ART initiation, 30.3% of non-IDU versus 42.5% of IDU had discontinued HAART (*P* < 0.001).
	Dissertation Published article	Kerr (2003) Title: Psychosocial determinants of maintenance of, and adherence to, antiretroviral therapy among injection drug users living with HIV/AIDS Kerr et al. (2005) Title: Determinants of HAART discontinuation among injection drug users	N=160	HIV-positive IDUs	Convenient sampling	Self-report Maintenance refers to the sustained use of ART, and is the opposite of discontinuation, which refers to the cessation of ART. Discontinuation: They had not picked up any components of their HAART regimen for one month.	In total, 71 (44%) participants discontinued HAART, and 89 (56%) remained on HAART. Variables that were negatively associated with ART maintenance included negative outcome expectations and incarceration. Variables that were associated positively with ART maintenance included efficacy expectations and

							self-regulatory efficacy. Efficacy expectations, self-regulatory efficacy, recent incarceration are negatively associated with HAART discontinuation
USA	Longitudinal study in New York	French et al. (2011) Title: Changes in Stress, Substance Use and Medication Beliefs are Associated with Changes in Adherence to HIV Antiretroviral Therapy	N=2089/4340 were included (48.1%)	HIV-positive substance users (use of cocaine, crack, heroin in the past 3 days)	Convenient sampling	Self-report: The number of pills prescribed per day and the number of doses they missed in the 3 days	71.7% of 2089 had ≤ 95% adherence Clients who changed from no substance use at one interview to substance use at the subsequent interview were approximately 2-3 times as likely to be consistently non-adherent. Clients who transitioned from being not sure to very sure about the effectiveness of ART were significantly more likely to transition

							from non-adherent to adherent. Clients who changed from low stress to high stress were three times more likely to change from adherent to non-adherent.
	Cross-sectional study in 9 states of the USA	Chitsaz et al. (2013) Title: Contribution of substance use disorders on HIV treatment outcomes and antiretroviral medication adherence among HIV-infected persons entering jail	N=1270	HIV-positive substance users	Convenient sampling	Self-report: The number of pills prescribed per day and the number of doses they missed in the 7 days	Among all subjects, 72% had used drugs in the 30 days. Drug use severity was negatively correlated with 1) having an HIV care provider, 2) being prescribed ART, 3) high levels of adherence (>95%) Being employed and paid for work was associated with a two-fold increased likelihood of optimal adherence. The commonly used drugs were marijuana,

							cocaine, and heroin.
	Cross-sectional study in multiple sites of USA	Sharpe et al. (2004) Title: Crack cocaine use and adherence to antiretroviral treatment among HIV-infected black women	N=785	HIV-positive black women	Convenient sampling	The outcome variable, ART adherence, was measured with a single question, “How often are you able to take the HIV/AIDS drugs exactly the way your doctor told you to take them?” The four-category Likert scale (always, usually, sometimes, rarely) was dichotomized into always and not always.	Crack users and users of other drugs were less likely than non-users to take their ART medicines exactly as prescribed
	Cross-sectional study in South Florida	Surratt et al. (2015) Title: Medication adherence challenges among HIV positive substance abusers: the role of food and housing insecurity	N=503	HIV-positive substance abusers (Heroin and Cocaine users)	Convenient sampling	Total ARV doses prescribed and total doses missed in the past 7 days	Nearly 60% of those reported ART diversion 47.2% achieved >95% adherence. Food/ housing insecurity was associated with lower HIV medication adherence.
	Cross-sectional study in USA	Shrestha and Copenhaver (2018)	N=133	HIV-infected methadone-	Convenient sampling	Self-report measure: percent of doses taken	One in five was not able to

		Title: Viral suppression among HIV infected methadone-maintained patients:The role of ongoing injection drug use and adherence to antiretroviral therapy (ART)		maintained patients		during the previous 30 days Optimal adherence means 95% adherence.	achieve viral suppression Opioid-dependent individuals who are stabilised on methadone remain at high risk for poor virologic suppression and increased HIV transmission
	Prospective observational study in Florida	Waldrop-Valverde et al. (2013) Title: Medication-Taking Self-Efficacy and Medication Adherence Among HIV-Infected Cocaine Users	N=99	HIV-infected Cocaine users	Convenient sampling	Using an electronic monitoring device (MEMs) and self-report Adherence was defined using percent of doses taken during the previous 7 days.	4-week interval for follow-up, over 6 month period Compared to the first month, there was a significant drop in adherence at Months 2, 3, 4, and 6 for percentage dose adherent. There was a reduction from 76.7 at Month 1 to 66.5 at Month 6 for percentage dose adherent (MEMs). From 66.4 at M1 to 57.3 at M6 for percentage days adherent (Self-report)

	Cross-sectional study	Harzke et al. (2004) Title: Psychosocial factors associated with adherence to antiretroviral medications in a sample of HIV-positive African American drug users	N=137	HIV-positive African American drug users	Convenient sampling	Self-rating their level of adherence (ranging from always missing doses to never missing doses)	Perceived efficacy of ART, and perceived barriers, simply forgetting to take medications were independently associated with adherence.
	Cross-sectional study	Hicks et al. (2007) Title: The impact of illicit drug use and substance abuse treatment on adherence to HAART	N=659	HIV-positive former, current, and never substance abusers	Convenient sampling	Self-report: The doses missed in the past 2 weeks. Adherence was defined as taking greater than or equal to 95% of prescribed doses of all antiretroviral drugs in the HAART regimen	67% had ≥ 95% adherence rate. Current users (60%) were significantly less likely to be adherent than former (68%) or never users (77%) Former users in substance abuse treatment were as adherent to HAART as never users Former users who had not received recent substance abuse treatment were significantly less adherent than never users Current substance users were significantly less

							adherent than never users, regardless of substance abuse treatment.
	Cross-sectional study	Carrico et al. (2010) Title: Affective Correlates of Stimulant Use and Adherence to Anti-retroviral Therapy Among HIV-positive Methamphetamine Users Carrico et al. (2007) Title: Affect Regulation, Stimulant Use, and Viral Load Among HIV-Positive Persons on Antiretroviral Therapy	N=122 N=858	HIV-positive methamphetamine users HIV-positive individuals (non-stimulant and stimulant users)	Convenient sampling	Self-report measure: percent of doses taken during the previous 7 days Optimal adherence means 100% adherence.	The majority of participants were MSM (94%). Among the MSM, 84% identified as predominantly or exclusively gay. Positive affect was independently associated with a decreased likelihood of reporting any injection drug use and an increased likelihood of reporting perfect ART adherence. Increase in affect regulation decreased the likelihood of regular stimulant use and non-adherence to ART
	A multisite cohort study	Mellins et al. (2009) Title: Adherence to antiretroviral medications and	N=1138	HIV-positive with mental and substance abuse disorders (49% IDUs)	Convenient sampling	Self-report: The number of missed doses in the past three days	Complete adherence in the past 3 days: 55% of the participants

		medical care in HIV-infected adults diagnosed with mental and substance abuse disorders					45% of those on ARVs reported skipping medications in the past three days The factors associated with non-adherence were current drug and alcohol abuse, increased psychological distress, less attendance at medical appointments, non-adherence to psychiatric medications and lower self-reported spirituality. Increased psychological distress was significantly associated with non-adherence, independent of substance abuse.
	Cross-sectional study	Magidson et al. (2015) Title: Can behavioural theory inform the understanding of depression and	N=83	Low-income HIV-positive substance abusers	Convenient sampling	Self-report: The number of doses missed versus doses prescribed over the past 4 days for all daily medications	Mean adherence rates ranged from 94.46 to 97.72 % in the past 4 days Crack use is significantly

		medication non-adherence among HIV-positive substance users? To test three components of behavioural depression theory—goal-directed activation, positive reinforcement, and environmental punishment					associated with missing doses There was only an indirect effect of environmental punishment; depressive symptoms were associated with greater non-adherence through greater environmental punishment. Goal-directed activation and positive reinforcement were unrelated to adherence.
	Cross-sectional study	Moore et al. (2012) Title: Methamphetamine use and neuropsychiatric factors are associated with antiretroviral nonadherence	N=125	67 HIV-positive lifetime meth users 50 HIV-positive non-meth users 8 HIV-positive current meth users	Convenient sampling	Self-report: Taken doses/prescribed doses in the past 4 days Non-adherence: Any skipped doses	Major depressive disorder uniquely predicted ART non-adherence after controlling for the other variables. Ancillary analyses indicated that current METH users (use within 30 days) were significantly less adherent than lifetime METH users and non-Meth users. Of

							those, neurocognitive impairment was associated with non-adherence.
	Cross-sectional study	Tucker et al. (2004) Title: Psychosocial Mediators of Antiretroviral Nonadherence in HIV-Positive Adults With Substance Use and Mental Health Problems	N=1889	HIV-positive individuals (23% of those were IDUs)	Convenient sampling	Self-report Adherence: Not missing any doses	46% of the participants were adherent Those in the drug use only group were not significantly more likely to be nonadherent than those with no mental health or substance use problems. Substance use group was more likely than those with no problems to have poor access. Drug use group was more likely to report poorer fit of the medication regimen with their lifestyle.

	Secondary data analysis from another study	Kelly et al. (2012) Title: Social Networks of Substance Users With HIV Infection: Application of the Norbeck Social Support Scale	N=76	HIV-positive individuals who use methadone	-	Self-report measure	The presence of network drug users and HIV-infected network members was associated with less antiretroviral medication adherence Note: The dependent variable, antiretroviral adherence, was assessed through self-report over the past 7 days at three-time points, baseline, Week 12, and Week 24. Adherence was dichotomized as either 100% (no missed doses or pills any time in the past week) or <100%.
	Prospective cohort study	Lucas et al. (2001) Title: Detrimental effects of continued illicit drug use on the treatment of HIV-1 infection	N=764	HIV-positive individuals	Convenient sampling	Self-report Nonadherence means participants report of more than two missed doses over the 2 weeks	Active drug users were more likely to be non-adherent Forty-four percent of active drug users failed to utilise HAART compared with

							22% of former drug users and 18% of non-drug users
	Longitudinal study	Hinkin et al. (2007) Title: Drug use and medication adherence among HIV-1 infected individuals	N=105	Stimulant users Non-stimulant users	Convenient sampling	MEMS caps Dividing actual dose events by prescribed doses during 1 month period Adherence: taking ≥ 90% doses	The drug-negative group's adherence rate was 79% as compared to 63% for the drug-positive group. Over time, adherence rates for the entire sample dropped from 74.4% for the first 2 months, to 68.5% for months 3–4, down to 62.6% for months 5 and 6 of the study Stimulant positive group's adherence rate was significantly lower than both the other-drug positive group (P = .001) as well as the non-drug group. Between group comparisons

							revealed a trend toward the cocaine + methamphetamine group evidencing poorer adherence than did the cocaine only group. The mean adherence rate for the cocaine only group was 68.1% vs. 54.5% for the cocaine + methamphetamine group. Drug use was associated with 4.1 times greater risk of being a poor adherer. Although the non-abuse group's mean adherence rates dropped 10% points, from 77.4% to 68.4%, the drug abuse group experienced a more precipitous decline with their mean adherence rate dropping over 18% points (from 70.1% to 51.3%).

	Cross-sectional study	Arnsten et al. (2007) Title: Factors Associated With Antiretroviral Therapy Adherence and Medication Errors Among HIV-Infected Injection Drug Users	N=636	HIV-infected drug users	Convenient sampling	Self-report Good adherence: taking ≥ 90% doses	75% (n=477) self-reported good adherence Depressive symptom and self-efficacy were associated with poor adherence.
	Prospective study	Arnsten et al. (2002) Title: Impact of active drug use on antiretroviral therapy adherence and viral suppression in HIV infected drug users	N=85	HIV-positive current and former drug users	Convenient sampling	MEMS caps (electronic pill caps) –Dividing the number of cap opening by the number of doses prescribed	Mean overall adherence was 53% Active cocaine use, female, not receiving social security benefits, not being married, positive for depression, the tendency to use alcohol or drugs to cope with stress were all associated with poor adherence. The strong predictor of poor adherence was active drug use. Adherence among active cocaine users was 20%, compared to 66% in subjects who

							did not use cocaine.
	Prospective study	Kalichman et al. (2015) Title: Intentional Medication Nonadherence Because of Interactive Toxicity Beliefs Among HIV-Positive Active Drug Users	N=530	HIV-positive drug users	Convenient sampling	Telephone-based unannounced pill counts over a 6-week period	189 (35%) participants indicated that they intentionally miss their ART when they are using drugs. These participants perceived hazards of mixing HIV medications with alcohol and other drugs. Participants who reported intentional nonadherence at the initial assessment were significantly more likely to have poorer adherence over the subsequent 6 weeks
	Retrospective cohort study	Turner et al. (2003) Title: Relationship of gender, depression, and health care delivery with antiretroviral	N=1827 (female) N= 3246 (male)	HIV-positive IDUs	Convenient sampling	Pharmacy-based measurement of adherence (filled prescription) Adherence means >95%	The mean adherence was 83.2% 22% of the study population were adherent at a 95% level.

		adherence in HIV-infected drug users					Adherence was higher among those who received regular drug treatment and psychiatric care Women were less adherent than men In women, adherence was significantly poor for those with cocaine or heroin use.

France	MANIF2000 Cohort study	Carrieri et al. (2003) Title: Failure to Maintain Adherence to HAART in a Cohort of French HIV-Positive Injecting Drug Users	N=96	HIV-positive IDUs	Convenient sampling	Adherence failure is defined as a self-reported, non-adherence behaviour at any visit before the 18th month of treatment. Adherence measure: the daily number of prescribed pills they have effectively taken during the week prior to the visit. Non-adherence means taking less than <80% of prescribed doses	22 (22.9%) experienced adherence failure, whereas 74 (77.1%) remained adherent at all follow-up visits. Lack of a stable relationship, active drug injection, and depression were independently associated with adherence failure.

		Moatti et al. (2000) Title: Adherence to HAART in French HIV-infected injecting drug users: the contribution of buprenorphine drug maintenance treatment	N=164	HIV-positive IDUs	Convenient sampling	Self-report Non-adherence means taking less than <80% of prescribed doses in the past 7 days	34.8% took less than 80% of the prescribed HAART doses during the previous week Non-adherence was associated with younger age, alcohol consumption, frequency of negative life-events during the prior 6 months and active drug use
		Bouhnik et al. (2002) Title: Nonadherence among HIV-infected injecting drug users: The impact of social instability	N=210	HIV-positive former or current IDUs	Convenient sampling	Self-report Non-adherence means taking less than <80% of prescribed doses	Among ex-IDUs, the only factor associated with nonadherence was social instability Among opioid-dependent patients, injection behaviour was the only determinant of nonadherence behaviour

		Roux et al. (2008) Title: The impact of methadone or buprenorphine treatment and ongoing injection on highly active Antiretroviral therapy (HAART) adherence: evidence from the MANIF2000 cohort study	N=276	HIV-positive IDUs	Convenient sampling	The visual analogue scale was used to reclassify as non-adherent those whose score was <100%. Patient's adherence to HAART in the 4 days and in the 4 weeks prior to the interview.	Patients ceasing injection during OST and abstinent patients exhibited comparable adherence. Patients reporting injection, on OST or not, had a twofold and threefold risk, respectively, of non-adherence compared with abstinent patients

The Netherlands	Prospective cohort study	Lambers et al. (2011) Title: Harm reduction intensity—Its role in HAART adherence amongst drug users in Amsterdam	N=102	HIV-positive drug users	Convenient sampling	Self-report measure: the number of days that medication was not taken in the last 6 months.	The rate of non-adherence (95%) ranged from a minimum rate of 6.2% (in 2002) to a maximum rate of 18.9% (in 2005) of the visits per year. Of the 76 participants who were adherent on their first included visit and who had a follow-up visit, 26 became non-adherent at least once in the study period. Non-injecting DUs with low dependence on harm reduction were less adherent than DU with complete harm reduction. Unsupervised housing (no access to structural support at home) and having a steady partner were significantly associated with respectively more

							and less non-adherence.
Vietnam	Prospective study	Jordan et al. (2014) Title: Correlates of non-adherence to antiretroviral therapy in a cohort of HIV-positive drug users receiving antiretroviral therapy in Hanoi, Vietnam	N=100	HIV-positive individuals with a history of drug use	Convenient sampling	Subjective rating (perfect, very good, good, fair, or poor adherence)	48% of participants reported drug use within the previous 6 months, with 22% reporting current drug use. Overall levels of self-reported ART adherence in this cohort were high (83% reporting perfect/very good adherence at the time of study enrollment) Active drug use and duration of ART increase the odds of suboptimal ART adherence

India	Cross-sectional study	Sharma et al. (2007) Title: Access, adherence, quality and impact of ARV provision to current and ex-injecting drug users in Manipur (India): An initial assessment	N=226	Current and ex-injecting drug users	Purposive sampling and convenient sampling	Treatment discontinuation	One-third of the sample reports ever having discontinued ART (74/226). Experience of side effects, whether ART is provided free, whether patients received counselling, and alcohol use was associated with ART discontinuation.

Summary of the included qualitative studies (N=11)

Country	Authors	Title of the article	Sample size	Sampling	Data collection method	Data analysis method	Major themes
USA	Batchelder et al. (2013	"Damaging what wasn't damaged already": Psychological tension and antiretroviral adherence among HIV-infected methadone-maintained drug users	15 HIV-positive drug users who use methadone maintenance	Convenient sampling	Semi-structured interviews	Thematic analysis	**Negative themes are related to continued drug use** 1. Denial and resistance 2. Shame 3. Perceived isolation **Positive themes are related to decreased drug use** 1. Acceptance of HIV and motivation to adhere 2. Empowerment 3. Perceived connectedness
	Pach et al. (2003)	A qualitative investigation of antiretroviral therapy among injection drug users	34 HIV-positive IDUs	Convenient sampling Snowball sampling	Ethnographic interviews	-	**Group 1 (N=8): Never on ART** 1. Involving in active drug use 2.Lacking information from health professionals about HAART 3. Having ambivalent or negative attitudes about the safety of the medication and the intentions of health care providers **Group2 (N=7): Stopped AZT and never sought other treatment.** 1. Active drug use 2. Lack of contact with HIV services 3. Negative experience with side effects from AZT 4. Exposure to negative attitudes about AZT deterred

Country	Authors	Title of the article	Sample size	Sampling	Data collection method	Data analysis method	Major themes
							members of this group from continuing their use of ART or later considering the use of ART **Group 3 (N=9): Stopped undergoing HAART** 1. Perceptions of HAART that altered in significance as their circumstances and experiences with the medication changed (e.g. level of drug use, lack of available drug treatment, severity of side effects, prior experience with clinicians) **Group 4 (N=10): Undergoing HAART** Working, living with relatives, receiving disability payments, improved health, trusted medical doctors, taking HAART in their own ways
	Ware et al. (2005)	Adherence, stereotyping and unequal HIV treatment for active users of illegal drugs	52 HIV-positive active drug users	Convenient sampling	Qualitative interviews	Analytic approach – Glaser and Strauss, Strauss and Corbin	1. Daily lives of participants 2. How drug use impedes adherence *Acquiring drugs * Consuming drugs *Recovering from drug use 3. Not carrying medication 4.Competing priorities 5. Redefining regimens 6. Efforts to adhere to HAART *Taking medications while using

Country	Authors	Title of the article	Sample size	Sampling	Data collection method	Data analysis method	Major themes
							*Prioritising adherence * Sticking with a set of rules: the significance of routines for adherence
Canada	Small et al. (2009)	The impact of incarceration upon adherence to HIV treatment among HIV positive injection drug users: A qualitative study	12 HIV-positive IDUs	Sampling at correctional settings	In-depth individual interviews	Thematic analysis	1. Entry into the correctional system and interruption of treatment 2. Difficulties accessing HIV medications within the correctional system 3. Challenges related to institutional health care services and HIV care 4. The importance of advocacy and communication 5. HIV discrimination amongst prisoners 6. Problems upon release to the community
	McNeil et al. (2017)	Antiretroviral therapy interruption among HIV positive people who use drugs in a setting with a community-wide HIV treatment-as-prevention initiative	39 HIV-positive drug users who had not filled an ART prescription for a period of at least 30 days	Purposeful sampling	Semi-structured interviews	Coding framework: individual and socio-structural influences	**Individual** 1.Individual and contextual influences on treatment fatigue 2. Negotiating prior adverse ART experiences 3. Social isolation and treatment motivation **Socio-structural** 1. Structural vulnerability and discontinuities in the continuity of HIV care
Russian	Rhodes and Sarang (2012)	Drug treatment and the conditionality of HIV treatment access: a	42 HIV-positive IDUs	Chain referral sampling	In-depth qualitative interviews	Thematic analysis	1. HIV treatment conditionality and delay

Country	Authors	Title of the article	Sample size	Sampling	Data collection method	Data analysis method	Major themes
		qualitative study in a Russian city	11 health practitioners				2. The problem of drugs in HIV treatment access 3. The problem of inadequate drug treatment
	Kiriazova et al. (2016)	"It is easier for me to shoot up": stigma, abandonment, and why HIV-positive drug users in Russia fail to link to HIV care	HIV-positive drug users	Convenient sampling	Individual interviews	Thematic analysis	1.Stigma and poor patient-provider relationships 2. Fragmentation of health care
Ukraine	Mimiaga et al. (2010)	"We fear the police, and the police fear us": structural and individual barriers and facilitators to HIV medication adherence among injection drug users in Kiev, Ukraine	16 HIV-positive IDUs	Convenient sampling	Two semi-structured focus groups	Content analysis	B**arriers** 1. Harassment and discrimination by police 2. Opioid dependence 3. Complexity of drug regimen 4. Side effects 5. forgetting 6. Co-occurring mental health problems 7. HIV stigma **Facilitators** 1. Cues for pill taking 2. Support and reminders from family, significant other, and friends 3. Opioid substitution therapy 4. Wanting improved health 5. Knowledge about HAART 6. Storage of medications 7. IDUs and sexual risk behaviours

Country	Authors	Title of the article	Sample size	Sampling	Data collection method	Data analysis method	Major themes
India	Chakrapani et al. (2014)	Barriers to antiretroviral treatment access for injecting drug users living with HIV in Chennai, South India	19 HIV-positive IDUs 4 key informants	Recruited by peer outreach workers	Semi-structured interviews	Framework analysis	**Family and social barriers** 1.Lack family support and fear of societal discrimination 2.Unmet basic needs - food and shelter **Health care system barriers** 1.Actual or perceived unfriendly hospital environment and procedures 2. Provider-perceived nonadherence 3. Actual or perceived inadequate counselling services and lack of confidentiality 4. Lack of effective linkages between ART centres, needle/syringe programs, and drug dependence treatment centres **Individual-level barriers** 1. Active drug use 2. Lack of self-efficacy and low motivation **Inadequate knowledge about ART**
Spain	De la Hera et al. (2011)	The opinions of injecting drug user HIV patients and health professionals on access to antiretroviral treatment and health services in Valencia, Spain	23 HIV-positive IDUs 9 health professionals	Convenient sampling	Semi-structured interviews	The codification process followed Strauss and Corbin's (1990) analytic procedure	**Health professionals** 1.Lack of coordination among hospital services 2. Difficulties in accessing non-specialised services 3. Their perceptions of a patient's likelihood of treatment adherence

Country	Authors	Title of the article	Sample size	Sampling	Data collection method	Data analysis method	Major themes
							IDUs 1. A good doctor-patient relationship 2. Family responsibility (Female participants) 3. Complexity and side effects of the treatment 4. lack of social support 5. active use of recreational drugs 6. Accessibility of services 7. Beliefs about HAART
The Netherlands	Witteveen and van Ameijden (2002)	Drug users and HIV combination therapy (HAART): Factors which impede or facilitate adherence	27 HIV-positive hard drug users	Convenient sampling	In-depth interviews	Glaser and Strauss's analytic approach	**Determinants in relation to the medication** 1. Side effects 2. Treatment regimen 3. Form and flavour **Determinants in relation to the individual** 1. Acceptance of the condition 2. Cognitive aspects 3. Mental health 4. Knowledge 5. Physical health 6. Material circumstances **Determinants in relation to the environment** 1. Relationship with health practitioners 2. Social support

Appendix 4: Information sheet and Consent form

Exploring the experiences with antiretroviral therapy among HIV-positive drug users: Constructivist grounded theory

Information sheet for participants

I would like to invite you to participate in this research project. You should only participate if you want to; choosing to not take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please contact me if there is anything that is not clear or if you would like more information. Thank you for taking time to read this information sheet.

Purpose of this research

To understand your experiences with HIV treatment.

Why have you been chosen?

You are being invited to take part in this study, as you have received HIV medications and have had the experiences of illicit drug use. Your participation can help us understand HIV-positive drug users' experiences with HIV treatment. Understanding your experiences with HIV treatment will

help us to recognise unforeseen issues and design services which are able to support the needs of people who are HIV positive and drug users.

Do I have to take part?

No, taking part is voluntary. If you don't want to take part, you do not have to give a reason and no pressure will be out on you to try and change your mind. You can pull out of the discussion at any time without penalty. If you decide to take part, you will be asked to sign the informed consent, and a copy of it will be given to you.

What is involved in participating?

You will be invited to take part in an interview about your experience with HIV treatment. The interview will take place in a private conference room at the National Taiwan University Hospital, Taiwan Lourdes Association, or Operation Dawn, and at the time most convenient for you. The interview will take approximately 30-60 minutes. It is intended as an opportunity for you to express your views and experiences of HIV treatment.

What will happen to the data after my interview?

The interview will be digitally-recorded, so that I don't forget important things that you say. All names will be removed during transcription and replaced with a code number. I will also remove names of places or organizations during transcription so that you cannot be identified.

All personal information will be kept separate from the interview transcripts to protect your anonymity. The digital files will be password protected at Szu-Szu Ho's computer, and all documents will be kept in Szu-Szu Ho's locked cabinet at the School of Health in Social Science at the University of Edinburgh. All of the research data will be confidential, and only Szu-Szu Ho, Dr Aisha Howlloway, Dr Rosie Stenhouse and the clinical supervisor Wang-Huei Sheng will have access to anonymised data following transcription. At

the end of the study, if you would like to know the findings of this study, I will give you a summary of anonymised findings.

It is also intended that research findings will be disseminated through journals and conferences. All results will be anonymised so that it is not identifiable to outsiders.

What are the benefits of participating?

There will be no direct benefit to you, although people often find it feels good to have some listen to their experiences. Your participation will benefit people who are drug users living with HIV through increased understanding of your experiences of HIV treatment. This understanding will help improve the support available to HIV-positive drug users.

What are the risks of participating?

There is no apparent risk of participation. If you feel uncomfortable talking about your experiences, you do not have to answer any question if you don't wish to do so. You do not have to give us any reason for not responding to any question, or for refusing to take part in the interview.

If you have any concerns or issues that you would like to discuss with someone in a therapeutic environment, a list of support or treatment services and contact information will be given to you following the participation of this study.

All of the interview data will be anonymised and kept confidential. However, there are limits to promises of confidentiality. You may not need to inform us of instances of harm to other people or illegal activity for which you have not already been convicted. The use of in-depth interviews in this study will allow you to have control of agenda and prevent over-disclosure.

Reimbursements

You will not be provided with any incentive to take part in the research. However, I will give you an NT$200 Seven-Eleven voucher (equivalent to 4 pounds) and pill boxes as a thanks gift for taking your time.

Who is the researcher?

My name is Szu-Szu Ho, studying PhD in Nursing Studies at the University of Edinburgh. I am a registered nurse who had previously worked at an infection unit of a medical centre. My research interest is to understand patients' health behaviour, particularly among people who are HIV-positive and/or drug misusers.

Contact information

If you are interested in taking part in this research and have any questions about this research, you may contact:

Szu-Szu Ho,

A PhD student at the University of Edinburgh

Email: s1225521@sms.ed.ac.uk; sisi863@hotmail.com

Tel: +886 0978356081; +44 07477463891

Line ID: sisi863

This proposal has been reviewed and approved by the Research Ethics Committees (RECs) at the National Taiwan University Hospital and the School of Health in Social Science at the University of Edinburgh, which are committees whose task is to make sure that research participants are protected from harm. If you wish to find more about the RECs, please contact:

School of Health in Social Science, University of Edinburgh

Email: Jo-Anne.Robertson@ed.ac.uk
Address: Medical School, Teviot Place, Edinburgh EH8

National Taiwan University Hospital

Tel: (02) 23123456 # 63160
Address: No.1, Changde St., Zhongzheng Dist., Taipei City 100, Taiwan (R.O.C.) Email: ntuhrec@ntuh.gov

Exploring the experiences with antiretroviral therapy among HIV-positive drug users: Constructivist grounded theory

Consent form

Participants:

By signing below,	Participant initials
I confirm that I have been informed of this study's information, and I have read the participant information sheet.	
I have been given the opportunity to ask questions before I sign, and any questions I asked have been answered to my satisfaction.	
I understand that participation is voluntary and that I can withdraw at any time without penalty.	
I agree that interviews will be digitally recorded.	
I understand that data will be anonymised and confidential, and will be stored and secured in accordance with data management policy at the University of Edinburgh.	
I understand that data will be confidential and kept secure at Szu-Szu Ho's computer and locked cabinet at the School of Health in Social Science. Only Szu-Szu Ho, Dr Aisha Howlloway, Dr Rosie Stenhouse and Dr Wang-Huei Sheng will have access to anonymised data following transcription.	

I agree that anonymised research findings will be disseminated through publication and conferences.	
I consent to participate in this study	

Signature of Participant _____

Date _____ Day/month/year

Researcher:

By signing below,	Researcher initials
I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands the purpose, the procedure, the benefits, and the risks that are involved in this research study.	
I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability.	
I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.	
A copy of this form has been provided to the participant.	

Signature of the principle investigator_____

Signature of the researcher taking consent_____

Date _____ Day/month/year

Appendix 5: Form of collecting socio-demographics

Socio-demographic characteristics (Code number:_____)
Age: _____
Gender ○ **Male** ○ **Female** ○ **Other_____**
Education ○ **Less than high school** ○ **High school or equivalent** ○ **College graduate** ○ **Postgraduate**
Main support source ○ **Spouse** ○ **Other family members** ○ **Friends** ○ **No one** ○ **Others_____**
Source of income ○ **Paid employment** ○ **Spouse /family** ○ **Welfare/unemployment** ○ **Others _____**
History of illegal drug use
Oral drug users_____/ Intravenous drug users____ **Current drug users_____/Past drug users____**
Substance use ○ **Heroin (☐ HIstoric ☐ Current)** ○ **Cocaine (☐ HIstoric ☐ Current)** ○ **Amphetamines (☐ HIstoric ☐ Current)** ○ **More than two illicit drugs (☐ HIstoric ☐ Current)**

○ Others _____
Length of drug use ○ Less than one year ○ 1-3 years ○ 3-5 years ○ > 5 years
Frequency of drug use if current use ○ < 1 time/ week ○ 2-3 times/ week ○ 4-6 times/ week ○ > 7 times/ week
Ever in drug withdrawal ○ Yes ○ No
Ever had methadone maintenance treatment/needle exchange programme/addiction therapy ○ Yes ☐ Methadone treatment (☐ current; ☐ historic) ☐ Needle exchange programme (☐ current; ☐ historic) ☐ Addition therapy (☐ current; ☐ historic) ○ No
HAART medications
How long have you been diagnosed with HIV positive
What HAART medications are you currently taking? (participants' pill bags) **Drug name/dose:**_____ _____ _____

_____ _____ _____
How long have you been on HAART medications? _____
How often did you follow HAART regimens? **☐ All of the time** **☐ Most of the time** **☐ About half of the time** **☐ Some of the time** **☐ Never**
When was the last time you missed taking any of your medications? **☐ Within the past week ____** **☐ 1-4 weeks ago ____** **☐ 1-3 months ago ____** **☐ More than 3 months ____** **☐ Never ____**

Appendix 6: A guideline for semi-structured interviews

Guideline for the semi-structured interviews
• Self-introducing the interviewer • Creating a comfortable and welcoming interview environment
Questions guideline (interview questions may change based on participants' answers)
Initial questions: • Tell me about your experience with being HIV positive. Probe: (5Ws) What HIV illness means to you? What contributed to this feeling? • Tell me about your experience with drug misuse. Probe: How you feel about this? Why? How you managed? • How does being HIV-positive and a drug misuse impact on your life? Probe: What happened? Under what conditions? Why? How you managed? • Please describe how you feel over the course of HIV illness and drug misuse? Probe: Tell me why your views have changed or remain the same? What have you learned?
• Tell me about your experiences with HIV treatment? Probe: (5Ws) • What does HIV treatment mean to you? Probe: What contributed to this feeling? • How do you feel before and after taking this regimen (At beginning versus years later)? Probe: Tell me why your views and/or actions may have changed (if any)? What have you learned? • Could you describe the lessons you learned through receiving this treatment? • Has there ever been a specific time when you haven't taken your medication? Probe: 1) Why? 2) Please describe the situation. 3) What contributed to this change or continuity? 4) What helps you to manage? • Who and what has been the most helpful to you over the course of this treatment? Probe: How has he/she/it been helpful?
Ending questions

- After having these experiences, what advice would you give to someone who has just started the treatment?
- Is there anything else you think I should know to understand better?
- Is there anything you would like to ask me?

Appendix 7: Criteria for assessing studies with constructivist grounded theory approaches (Charmaz, 2014)

Credibility (Chapter 5-8)	Has your research achieved intimate familiarity with the setting or topic?	√
	Are the data sufficient to merit your claims?	√
	Have you made a systematic comparison?	√
	Do the categories cover a wide range of empirical observations?	√
	Are there strong logical links between the gathered data and your argument and analysis?	√
	Has your research provided enough evidence for your claims to allow the readers to agree with your claims	√
Originality (Chapter 6-9)	Are your categories fresh? Do they offer new insights?	√
	Does your analysis provide a new conceptual rendering of the data?	√
	What is the social and theoretical significance of this work?	√
	How does your grounded theory challenge, extend, or refine current ideas, concepts and practices?	√
Resonance (Chapter 5-8)	Do the categories portray the fullness of the studied experience?	√
	Have you revealed both liminal and unstable taken-for-granted meanings?	√
	Have you drawn links between larger collectivises or institutions and individual lives, when the data so indicate?	√

	Does your grounded theory make sense to your participants or people who share their circumstances? Does your analysis offer them deeper insights about their lives and worlds?	Did not do member check
Usefulness (Chapter 6-9)	Does your analysis offer interpretation that people can use in their everyday worlds?	√
	Do your analytic categories suggest any generic processes?	√
	If so, have you examined these generic processes for tacit implications?	√
	Can the analysis spark further research in other substantive area?	√
	How does your work contribute o knowledge? How does it contribute to making a better world?	√